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The Essence of Functioning in Sleep Disorders -

Development of a Core Set of Categories of the International

Classification of Functioning, Disability and Health (ICF)

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Executive Summary

This doctoral project seeks to answer the question about the essence of functioning, disability and health in the lived experience of persons with any kind of primary sleep disorder. Its overall objective is the development of a first version of Core Sets of categories of the International Classification of Functioning, Disability and Health (ICF) in an evidence- and consensus-based process. To this end, four separate studies exploring different perspectives (researcher, clinical, patient, health professional) have been conducted and their results provided the evidence basis for selecting the relevant categories for the ICF Core Sets for Sleep Disorders during an international consensus conference. The doctoral thesis first-authored by the doctoral candidate therefore consists of five separate publications (1 Systematic Review, 2 Patient Studies, 1 Expert Survey, 1 Conference Results) that describe the different steps in the development process.

Zusammenfassung

Diese Doktorarbeit sucht die Frage nach der Essenz der gelebten Erfahrung von Menschen mit jeglicher Art von primärer Schlafstörung im Hinblick auf Funktionsfähigkeit, Behinderung und Gesundheit zu beantworten. Das übergeordnete Ziel ist dabei die Entwicklung einer ersten Version von Kerndatensätzen von Kategorien der Internationalen Klassifikation für Funktionsfähigkeit, Behinderung und Gesundheit (ICF) in einem auf Evidenz und Konsens basierenden Prozess. Zu diesem Zweck wurden vier separate Studien durchgeführt die verschiedene Perspektiven erörtern (Forscher, Klinik, Patient, Experte) und deren Resultate als Entscheidungsgrundlage für die ICF Core Sets für Schlafstörungen auf einer internationalen Konsensuskonferenz verwendet wurden. Die vom Prüfling eigenverantwortlich durchgeführten Studien und Entwicklungsschritte entsprechen demnach einer kumulativen Dissertation aus fünf Einzelpublikationen (1 Systematischer Literaturbericht, 2 Patientenstudien, 1 Expertenbefragung, 1 Konferenzergebnisse).

Content

<u>Background</u>

Sleep is a universal human need, about a third of our lives we spent asleep. **Sleep and sleep related disorders therefore play an important role in relation to health**. The International Classification of Sleep Disorders ICSD-2 (1) identifies six distinct fields of sleep disorders with over eighty different diagnoses. The six distinct fields comprise insomnia, sleep related breathing disorders, hypersomnias, sleep related movement disorders, circadian rhythm sleep disorders, and parasomnias, whereas the first four are the most frequent.

Involuntary naps, sleep attacks and drowsiness are hallmarks of excessive daytime sleepiness (EDS), a consequence common to the vast majority of patients with a sleep disorder (2-4).

However, not only the prevalence rates, diagnoses and symptoms are relevant when sleep disorders are described but also **how they manifest in the lived experience of persons with sleep disorders**. We know that sleep disorders also extend to health-related aspects of this lived experience. Especially, poor performance at work or school, disruption of family life, and frequent accidents (5) and the impact of these consequences on quality of life (6), the work environment, economy and health care expenditure are considerable (7-9).

The recognition of the importance of systematically assessing symptoms, problems in functioning and quality of life to optimize the management of patients with sleep disorders is increasingly influencing the clinical practice and research in the field of sleep medicine (10-17). Irrespective of the clinical context and the health-care situation in which sleep disorders manifest, **an in-depth understanding, systematic consideration and solid description of the whole range of functional problems associated with sleep disorders are necessary**.

The classification systems relevant to sleep medicine like the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)(18) and the ICSD-2 seek to give credit to the important impact on a person's daytime functioning.

Both classifications use operational and broad definitions of problems in functioning as diagnostic criteria of the health conditions they seek to capture. Looking at insomnia as an example, the DSM-V uses the expression of 'causing significant distress or daytime impairments in social, occupational or other sectors of daily life' without further specification, whereas ICSD-2 captures the functioning properties and essential criteria of insomnia in nine different 'forms of daytime impairment'.

It is therefore important to specifically define those problems in functioning and moreover to do so for all sleep disorders. The International Classification of Functioning, Disability and Health (ICF)(19) offers a globally agreed-on framework for a **more detailed and comprehensive understanding of the components of health and health-related states.** It thereby complements classification systems like the International Classification of Diseases (ICD-10th revision)(20) or DSM-V and ICSD-2. It therefore seems an adequate tool to systematically and comprehensively explore the essence of the lived experience of sleep disorders. The ICF framework is based on a bio-psycho-social model of health and provides added value to the conceptualization of quality of life by including codes for the component environmental factors (21).

ICF was approved and unanimously endorsed by all member states at the 54th World Health Assembly in May 2001. The ICF and its model achieve a synthesis and provide a coherent view of the different perspectives of functioning and disability from the biological, individual, and social perspectives. Thus, based on the ICF, the management of functioning and disability requires a comprehensive approach that not only targets aspects intrinsic to the person but also aspects of the environment, and requires actions be taken across sectors that include health, labor, education and social-affairs.

The model identifies three components of the dimension functioning, namely body functions and structures, activities, and participation. Problems or difficulties in these components that represent disability are called impairments, activity limitations, and participation restrictions. Functioning and disability are both affected by interactions between health conditions and contextual factors (environmental and personal).

The ICF consist of more than 1400 categories to describe patient's functioning, disability, and health. This project seeks to answer the question of what are the categories of functioning in ICF that essentially address sleep disorders.

These will be used in combination with other diagnostic classifications such as ICD-10, DSM-V or ICSD-2 to describe problems in functioning as an addition to the diagnostic criteria. These sets of categories relevant to persons with sleep disorders are called ICF Core Sets. The overall objective of this doctoral project is therefore the **development of a first version of ICF Core Sets for Sleep Disorders in an evidence- and consensus-based process**.

To this end, four specific studies which are addressing four different perspectives (researcher, clinical, patient, health professional) and a consensus conference have

been performed. The results of the four studies and the results of the consensus conference have been published separately in international, peer-reviewed sleep journals and are summarized in the following paragraphs.

Specific Studies

The **systematic review and content comparison** representing the perspective of the researcher was published as:

- **Gradinger F**, Glässel A, Bentley A, Stucki A. Content Comparison of 115 Health-Status Measures in Sleep Medicine using the International Classification of Functioning, Disability and Health (ICF) as a reference. submitted to *Sleep Medicine Reviews* (IF: 6.143) on 30.03.10
  Accepted: 02.07.10

The ICF has been proven to be a useful reference system to compare the content of outcome measures of health-related quality of life in general (22) and for sleep related breathing disorders in particular (23). However, a global estimation of the different questionnaires used in sleep medicine has not been done so far. The objective of this review and content comparison was therefore to systematically identify and quantify the concepts contained in health status measures in sleep medicine practice and research using the ICF as a reference.

A systematic literature review was conducted in order to identify and select generic and condition-specific patient-administered measures/questionnaires used in sleep medicine practice and research. A comprehensive search strategy for reviews, national/international guidelines and standard references to ensure that all areas of functioning, disability and health are captured, was employed. In a further step the contents of the selected measures were identified and linked to the ICF using established linking rules. The frequencies of ICF categories covering the concepts contained in the measures were used for the descriptive analysis and content comparison.

Overall, 115 patient-administered measures were analyzed. Of these, 35 were of generic nature and 17 were symptom-related (eight sleepiness/six fatigue/two alertness/one tiredness). There were 63 condition-specific measures including 38 for Insomnia, 11 for Sleep Apnea, 10 for Restless Legs Syndrome, and 4 Narcolepsy questionnaires.

Overall, the 4686 meaningful concepts contained in the items of all the sleep measures were linked to 133 different 2nd level ICF categories. Predominantly these were linked to 54 different ICF categories of the ICF component body functions

(61.4%), followed by 15.3% of concepts linked to 49 different categories of the component activities & participation, and 9.8% of concepts linked to 22 categories of the component environmental factors. The component body structures was the least frequent (0.5%). Table 1 shows the top five of most frequently mentioned ICF categories for each ICF component.

Table 1: Systematic Review - Most frequently mentioned ICF Categories
(*Percentage of Measures mentioning respective category)

TOP 5	Body Functions	%*
b134	Sleep functions	88
b130	Energy and drive Functions	57
b152	Emotional functions	48
b126	Temperament and personality functions	41
b110	Consciousness functions	30
TOP 5	Body Structures	%
s750	Structutre of lower extremity	4
s710	Structure of head and neck region	2
s730	Structure of upper extremity	2
s740	Structure of pelvic region	1
s720	Structure of shoulder region	1

TOP 5	Activities & Participation	%
d920	Recreation and Leisure	32
d850	Remunerative employment	29
d230	Carrying out daily routine	22
d415	Maintaining a body position	19
d475	Driving	17
TOP 5	Environmental Factors	%
e110	Products or substances for personal consumption	33
e250	Sound	22
e245	Time-related changes	20
e310	Immediate family	11
e580	Health services, systems and policies	9

The study is both comprehensive in the range of questionnaires covered and also in the application of a reference system that seeks to capture all aspects of health. The measures vary greatly with regard to the number and specificity of the ICF categories covered, as indicated by the proportional indices of content density and content diversity that are displayed in the league table in the publication. The ICF provides a useful reference to identify and quantify the concepts contained in health status measures used in sleep medicine practice and research.

All work related to identifying, retrieving and analyzing the data and the writing of the related paper were undertaken by the doctoral candidate.

The **empirical, cross-sectional study** representing persons with any kind of (primary) sleep disorders in a clinical setting was published as:

- **Gradinger F**, Glässel A, Gugger M, Cieza A, Braun N, Khatami R, Schmitt W, Mathis J. Identification of problems in functioning of persons with sleep disorders in a clinical setting using the International Classification of Functioning Disability and Health (ICF)-Checklist.
  Submitted to *Journal of Sleep Research* (IF: 3.255) on 02.03.10
  Accepted: 20.08.2010

This is an explorative, cross-sectional, multi-centre study that sought to identify the most common problems of persons with any kind of (primary) sleep disorder in a

clinical setting using the International Classification of Functioning, Disability and Health (ICF) as a frame of reference. A convenience sample of patients of any etiopathology of a primary sleep disorder was consecutively recruited in the sleep centers of the University clinics of Berne and Zurich and the Clinic Barmelweid (all Switzerland), each in different Swiss cantons (provinces). Data was collected through a structured face-to-face Interview with patients of 45-60 minutes. A case record form which was coded by health professionals contained the extended ICF Checklist (24), socio-demographic variables, and disease specific variables was used. The study centers collected data of 99 individuals with any kind of primary sleep disorder.

The identified categories include 48 (32%) for body functions, 13 (9%) body structures, 55 (37%) activities and participation and 32 (22%) for environmental factors. Table 2 shows the top five of most frequently mentioned ICF categories for each ICF component.

Table 2: Empirical Study - Most frequently mentioned ICF Categories
(*Percentage of patients mentioning respective category)

TOP 5	Body Functions	%*
b134	Sleep functions	100
b130	Energy and drive functions	85
b140	Attention functions	78
b126	Temperament and personality functions	77
b450	Additional respiratory functions	71
TOP 5	**Body Structures**	**%***
s430	Structure of respiratory system	53
s410	Structure of cardiovascular system	30
s320	Structure of mouth	19
s110	Structure of brain	15
s120	Spinal cord and related structures	13

TOP 5	Activities & Participation	%*
d110	Watching	82
d920	Recreation and Leisure	75
d230	Carrying out daily routine	74
d115	Reading	73
d470	Using transportation	70
TOP 5	**Environmental Factors**	**%***
e310	Immediate family	86
e580	Health services, systems and policies	81
e110	Products or substances for personal consumption	75
e355	Health professionals	72
e245	Time-related changes	64

This study shows that sleep disorders are associated not only with a large number of impairments in body functions and body structures but also with activity limitations and participation restrictions, and that the environment can play an essential role in the life of persons with sleep disorders. The ICF has potential to provide a comprehensive framework for the description of functional health in individuals with sleep disorders in a clinical setting.

All the work related to the logistics within the three study centers (including ethics committee approval) as well as the data collection and analysis and its reporting in written form were performed by the doctoral candidate.

The **qualitative study** using focus groups in order to explore the perspective of persons with sleep disorders was published as:

- **Gradinger F**, Köhler B, Khatami R, Mathis J, Cieza A, Bassetti C. Problems in functioning from the patient perspective using the International Classification of Functioning, Disability and Health (ICF) as a reference.

  Submitted to *Journal of Sleep Research* (IF: 3.255) on 02.03.10,

  Accepted: 08.05.10

This is a qualitative, multicenter study using a focus group design to explore the lived experiences of persons with any kind of primary sleep disorder with regard to functioning and contextual factors. Six open-ended questions related to the ICF components were used to classify the results using the International Classification of Functioning, Disability and Health (ICF) as a frame of reference.

The units of analysis were the meaningful concepts within the transcribed data and which was linked to ICF categories according to established linking rules (25-26). The six focus groups with 27 participants yielded a total of 6986 relevant concepts which were linked to a total of 168 different 2nd-level ICF categories.

Out of these 168 categories, 53 (31.5%) categories belong to Body Functions, 57 (33.9%) categories to Activities and Participation, and 48 (28.6%) categories belong Environmental Factors. Ten (6%) categories referred to Body Structures.

Table 3: Qualitative Study - Most frequently mentioned ICF Categories
(*Number of focus groups that mentioned category / Overall number of linkings to this category)

TOP 5	Body Functions	N of focus groups/N of linkings*
b134	Sleep functions	6 / 486
b130	Energy and drive Functions	6 / 375
b126	Temperament and personality functions	6 / 175
b140	Attention functions	6 / 46
b455	Exercise tolerance functions	6 / 38

TOP 5	Body Structures	N of focus groups/N of linkings*
s750	Structure of lower extremity	4 / 14
s710	Structure of head and neck region	3 / 3
s730	Structure of upper extremity	2 / 8
s310	Structure of nose	2 / 2
s760	Structure of trunk	1 / 11

TOP 5	Activities & Participation	N of focus groups/N of linkings*
d850	Remunerative Employment	6 / 212
d920	Recreation and leisure	6 / 190
d230	Carrying out daily routine	6 / 106
d415	Maintaining body position	6 / 50
d240	Handling stress and other psychological demands	6 / 50

TOP 5	Environmental Factors	N of focus groups/N of linkings*
e310	Immediate family	6 / 168
e110	Products or substances for personal consumption	6 / 149
e410	Individual attitudes of immediate family	6 / 96
e580	Health services, systems and policies	6 / 85
e355	Health professionals	6 / 84

Out of the total number of concepts, 1843 concepts (26%) were assigned to the ICF component Personal Factors, which is not yet classified but could indicate important aspects of resource management and strategy development of those who have a sleep disorder. Therefore, treatment of patients with sleep disorders must not be limited to anatomical and (patho-) physiologic changes, but should also consider a more comprehensive view which includes patient's demands, strategies and resources in daily life and the context around the individual.

All the work related to the logistics within the three study centers (including ethics committee approval) as well as the data collection and analysis and its reporting in written form were performed by the doctoral candidate.

The **expert survey** with health professionals from different professions worldwide was published as:

- **Gradinger F**, Boldt C, Högl B, Cieza A. Identification of problems in functioning of persons with sleep disorders from the health professional perspective using the International Classification of Functioning, Disability and Health (ICF) as a reference.

  Submitted to *Sleep Medicine* (IF: 3.163) on 18.02.10

  Accepted: 31.08.2010

This is an international expert survey which looked to identify relevant aspects of functioning as well as related environmental factors of patient with sleep disorders from the perspective of health professionals that treat them. A structured email survey was sent to 174 selected international experts experienced in the treatment of sleep disorders including physicians, nurses, therapists, technicians, biologists and psychologists. The same 6 open-ended questions that were used in the qualitative study were applied in the survey. All answers were translated ('linked') to the ICF based on established coding rules.

One hundred and twenty-three experts (70.7 %) from 6 WHO regions (54 countries) mentioned 5.200 themes which were linked to 7260 ICF categories. Of these 189 different ICF 2nd level categories, 31% belonged to the component Body Functions, 15% to Body Structures, 26% to Activities and Participation, and 28% to Environmental Factors.

Table 4: Expert Survey - Most frequently mentioned ICF Categories
(*Percentage of experts mentioning respective category)

TOP 5	Body Functions	%*
b134	Sleep functions	85
b130	Energy and drive Functions	72
b140	Attention functions	71
b126	Temperament and personality functions	59
b144	Memory functions	50

TOP 5	Body Structures	%*
s110	Structure of brain	61
s410	Structure of cardiovascular system	42
s430	Structure of respiratory system	35
s330	Structure of pharynx	24
s310	Structure of nose	23

TOP 5	Activities & Participation	%*
d570	Looking after one's health	72
d850	Remunerative employment	64
d475	Driving	58
d855	Non-renumerative employment	27
d770	Intimate relationships	24

TOP 5	Environmental Factors	%*
e580	Health services, systems and policies	89
e110	Products or substances for personal consumption	51
e310	Immediate family	43
e115	Products and technology for personal use in daily living	38
e590	Labour and employment services, systems and policies	37

This is the first survey that explores the functional problems of individuals with sleep disorders from a worldwide perspective and that is involving most of the different health professions related to the treatment of these disorders. Health professionals addressed a large variety of functional problems reflecting the complexity of sleep disorders. The ICF provided a comprehensive framework in order to integrate answers from different professional backgrounds and different world regions.

All the steps of the survey including the compilation and recruitment of participants, data analysis and reporting were done by the doctoral candidate.

ICF Core Sets for Sleep Disorders

The results of the international **consensus conference** were published as:

- **Gradinger F**, Cieza A, Stucki A, Michel F, Bentley A, Oksenberg A, Rogers AE, Stucki G, Partinen M. International Classification of Functioning, Disability and Health (ICF) - ICF Core Sets for Persons with Sleep Disorders: Results of the Consensus Process integrating Evidence from Preparatory Studies.
  Submitted to *Sleep Medicine* (IF: 3.163) on 18.02.10
  Accepted: 31.08.2010

A formal decision-making and consensus process which integrated evidence gathered from preparatory studies was performed. The resulting proposal for the Comprehensive and Brief 1st Versions of the ICF Core Set for Sleep Disorders are reported. The relevant ICF categories were selected by a sample of international experts from different professional backgrounds in a formal consensus process using the nominal group technique.

Two types of ICF Core Sets have been adopted during the international consensus conference. **Comprehensive ICF Core Sets** include the prototypical spectrum of problems in functioning in patients with a specific condition. They have been developed to guide multi-professional comprehensive assessment and to include as few as possible, but as many as necessary ICF categories to sufficiently describe patients' functioning. The **Brief ICF Core Sets** can serve as minimum data sets to be reported in every clinical study and to be assessed at any clinical encounter involving patients with the specific health condition. They include the most important categories in any situation, setting, country or culture (27). It is important to note that ICF Core Sets for Sleep Disorders are not a health status measure in their own right. They are intended as an international standard of what to measure and report (not how to measure it), and aim to facilitate the interpretation and aggregation of data for health information.

Twenty-six experts from 22 countries and different professional backgrounds attended the consensus conference. Altogether 120 second- or third-level ICF categories were included in the Comprehensive ICF Core Set with the following ICF components: 49 categories from body functions, 8 from body structures, 31 from activities and participation and 32 from environmental factors. The Brief ICF Core Set is depicted in table 5 below.

Table 5: Brief ICF Core Set for Sleep Disorders

ICF code	Title
Component	Body Functions
b134	Sleep functions
b130	Energy and drive functions
b140	Attention functions
b110	Consciousness functions
b440	Respiration functions
Component	Body Structures
s110	Structure of brain
s430	Structure of respiratory system
s330	Structure of pharynx
Component	Activities & Participation
d160	Focusing attention
d475	Driving
d240	Handling stress and other psychological demands
d230	Carrying out daily routine
Component	Environmental Factors
e310	Immediate family
e580	Health services, systems and policies
e355	Health professionals

All of the varying aspect of project-managing the international consensus conference were supervised and performed by the doctoral candidate.

Outlook

This dissertation set the ground for furnishing a bio-psycho-social outlook on all health and health-related aspects of the lived experience of any kind of sleep disorder based on the ICF model and classification system.

Nighttime disordered sleep manifests in daytime impairments, limited activities, and restricted participation. It does so in interaction with the individual living context of the person concerned. Systematically delivering evidence for these relationships adds essential rationale to raising awareness about and better recognizing sleep disorders - a student falling asleep during classes might not be lazy but actually be suffering from disordered sleep!

Besides having come up with an evidence- and consensus-based core data set of categories of the ICF relevant to sleep disorders, the dissertation generated additional methodological, practical and meaningful value for the field of sleep medicine as a whole.

Especially the league tables of existing sleep questionnaires published in the most widely read international sleep journal could be used as global resources for sleep clinicians and researchers working on any continent or in any language. It will help clinicians and researchers make more informed choices about which patient-reported questionnaires to use in their work.

Both patient studies present new methodologies as well as results that incite a more profound understanding of the individual patient living with a sleep disorder. The patient studies deliver ample and pivotal evidence for the inclusion of contextual factors in the interactive treatment of these patients. These are evidently critical for the enabling and disabling factors in the disease process. Advocating for including the anamnestic question: How is it going at home/work? in any clinical proceeding would be a starting point.

However, before systematically including the categories of the Core Sets in implementation activities, further validation and ongoing improvements in Phase II of the project seem indicated. These could involve looking at intercultural perspectives and increasing the representativeness of patients with sleep disorders through a concerted and combined international effort. The ICF Core Sets for Sleep Disorders are being designed with the aim to provide **useful standards for research, clinical practice and teaching**. It is hypothesized that the ICF Core Sets for Sleep Disorders will stimulate research and eventually bring forth a more integrated understanding of functioning, disability, and health in sleep medicine. It is furthermore the aim that such research will lead to interventions and accommodations that improve the restoration and maintenance of functioning and that minimize disability among persons with sleep disorders throughout the world.

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Content Comparison of 115 Health-Status Measures in Sleep Medicine using the International Classification of Functioning, Disability and Health (ICF) as a reference

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Short title: ICF Content Comparison of 115 Health-Status Measures

Abstract

The objective of this systematic review and content analysis was to identify and quantify the concepts contained in patient-administered health status measures in sleep medicine practice and research using the International Classification of Functioning, Disability and Health (ICF) as a reference.

Both generic and condition-specific patient-administered measures/questionnaires used in sleep medicine practice and research were identified and selected. A comprehensive search strategy for reviews, national/international guidelines and standard references to ensure that all areas of functioning, disability and health were captured was used. The contents of the selected measures were examined and linked to the ICF using established linking rules. The frequencies of ICF categories covering the concepts contained in the 115 patient-administered measures were used for the descriptive analysis and content comparison.

Of these, 35 were of a generic nature, 17 were symptom-related, and 63 condition-specific. The concepts identified in the questionnaires' items were predominantly linked to categories of the ICF component related to body functions (61.4%), followed by activities & participation (15.3%), and then environmental factors (9.8%). The measures vary greatly with regard to the number and specificity of the ICF categories covered, as indicated by the proportional indices of content density and content diversity. The ICF provides a useful reference to identify, quantify and compare the concepts contained in health status measures used in sleep medicine practice and research.

INTRODUCTION:

Sleep deprivation and sleep disorders are important public health issues (1) presenting with a wide spectrum of complaints including fatigue, lethargy, drowsiness, reduced attention and concentration, headaches, memory deficits, irritability, anxiety, depressive symptoms, poor performance at work or school, disruption of family life, and frequent accidents (2). The impact of these consequences on quality of life (3), the work environment, economy and health care expenditure are considerable (4-6).

The sheer number of 88 different diagnoses, as classified in the second edition of the International Classification of Sleep Disorders (ICSD-2) (7), makes the field of sleep medicine a uniquely complex, inter-disciplinary and challenging clinical and research environment. Simply arriving at the correct diagnosis does not explain what individuals living with a sleep disorder are actually able to do, what their needs are, how their environment comes into play, what their trajectory and prognosis are and what the cost of treatment will be.

Various organisations have published statements which have highlighted the importance of the systematic assessment of symptoms, functional limitations and quality of life in order to optimize the management of patients with sleep disorders (8-14).

In order to provide a common framework for functional health outcome measurement that seeks to answer the above questions, the International Classification of Functioning, Disability and Health (ICF) (15) was developed. The ICF answers the needs for common definitions, anchor points and a consensus on the conceptual framework capturing the functional problems associated with health conditions and diseases that appear on a continuum between functioning and disability and that are conceptualized in interaction with contextual factors. In accordance with the World Health Organization's policy, it thereby complements and completes the manifestation properties (signs & symptoms) of diseases as specified in the International Classification of Diseases, 10th revision (ICD-10) (16, 17).

The ICF consists of two major parts. The first covers Functioning and Disability (part 1) the second Contextual Factors (part 2). Each of these subdivisions is further divided into 'components': with body functions (code-b) and body structures (code-s) plus activities and participation (code-d) subsumed under Functioning and Disability, and environmental factors (code-e), and personal factors (pf) subsumed under

Contextual factors. The letters representing each component are followed by a numeric code that defines the chapter number (first digit) and category levels up to the fourth level (suffix of two, three, or four digits), apart from personal factors where no categories exist as of yet.

As an example, mental functions (from chapter 1 under body functions) would be represented by the following:

'b1 Mental functions' (first/chapter level)

       'b134 Sleep functions' (second level)

             'b1340 Amount of sleep' (third level)

             'b1341 Onset of sleep' (third level)

             'b1342 Maintenance of sleep' (third level)

             'b1343 Quality of sleep' (third level)

             'b1344 Functions involving the sleep cycle' (third level)

With the use of the bio-psycho-social model of ICF it becomes possible to integrate crucial information for the depiction of the lived experience of persons with a certain health condition in an interactive, dynamic and comprehensive way (Figure 1a). A simulated case example related to sleep apnea is given in Figure 1b.

Figure 1a: ICF Model
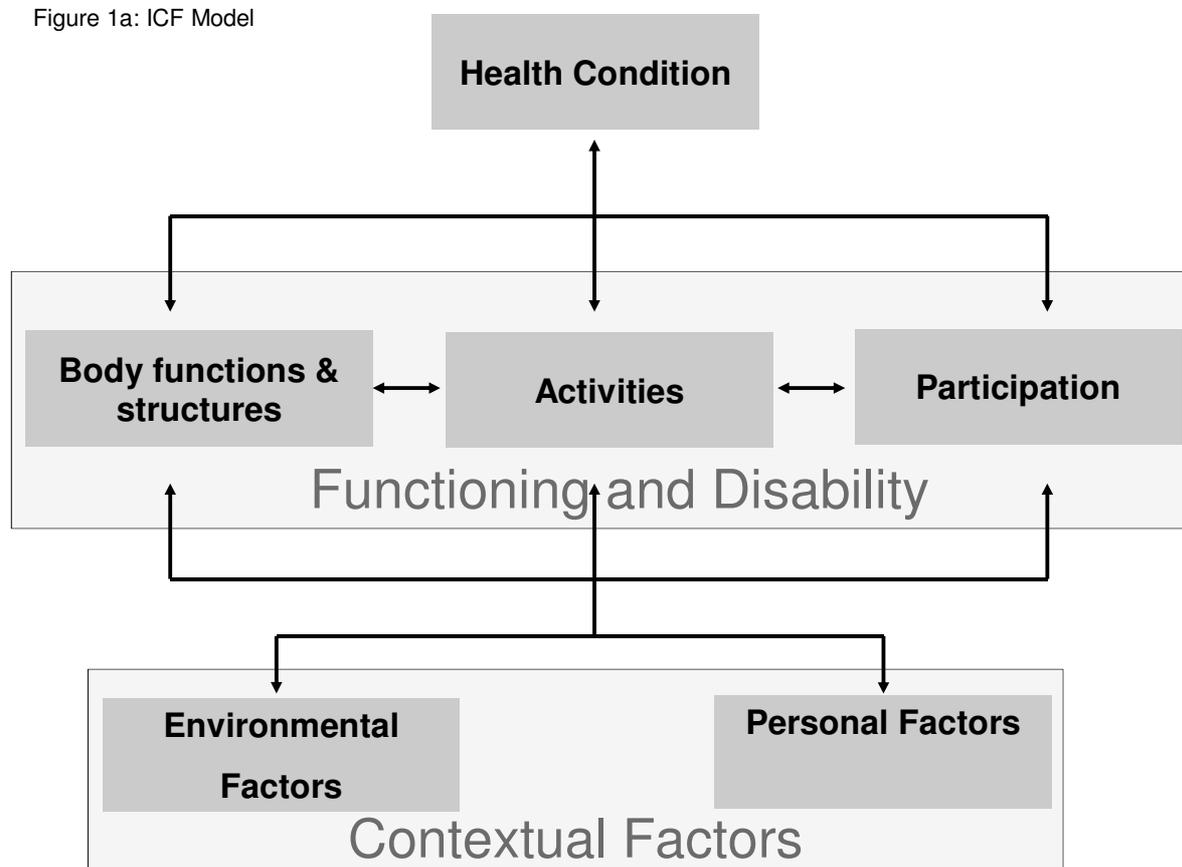
Figure 1b: ICF Model
with case example
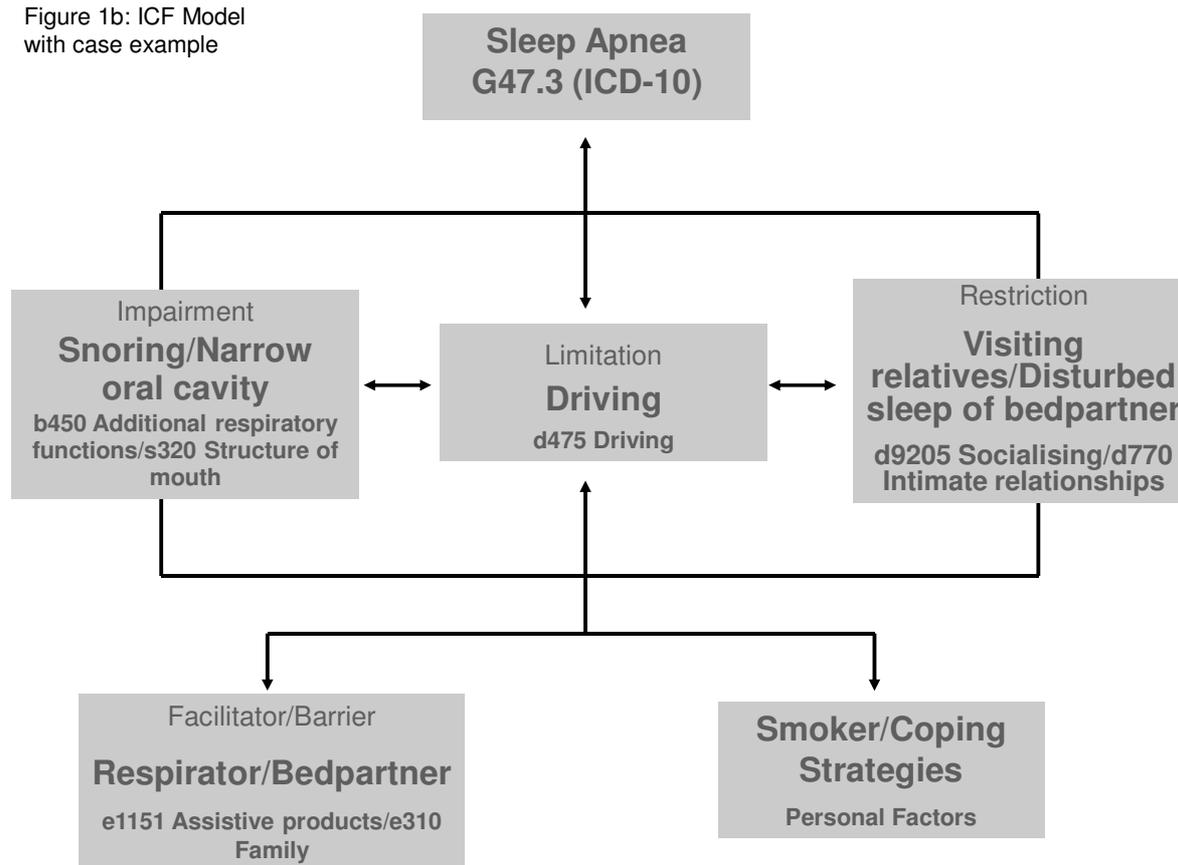
Sleep Apnea
G47.3 (ICD-10)

Impairment
Snoring/Narrow oral cavity
b450 Additional respiratory functions/s320 Structure of mouth

Limitation
Driving
d475 Driving

Restriction
Visiting relatives/Disturbed sleep of bedpartner
d9205 Socialising/d770 Intimate relationships

Facilitator/Barrier
Respirator/Bedpartner
e1151 Assistive products/e310 Family

Smoker/Coping Strategies
Personal Factors

The classification systems relevant to sleep medicine like the Diagnostic and Statistical Manual of Mental Disorders, 4th edition text revised (DSM-IV-TR)(18) and the ICSD-2 can benefit from the bio-psycho-social grid provided by ICF. Both classifications use some operational and broad definitions of functional manifestations in the diagnostic criteria of the health conditions they seek to define. For insomnia, the DSM-IV-TR uses the expression of 'causing significant distress or daytime impairments in social, occupational or other sectors of daily life' without further specification, whereas ICSD-2 captures the functioning properties and essential criteria of insomnia in nine different 'forms of daytime impairment'. The ICF offers a more detailed and comprehensive framework to specify functioning in its component activities and participation as well as adding value to the conceptualisation of quality of life by including environmental factors (19).

Many of the existing sleep measures have been reviewed and grouped with regard to their use and psychometric properties (20-31)* but as the first and most important quality criteria are face and content validity (32), content comparisons are rarely presented. Such a content comparison using a universally accepted, well-defined,

and standardized reference system, that allows for a comprehensive exploration and comparison of all contents of the existing and currently used measures would be valuable. However, a global estimation of the different questionnaires used in sleep medicine has not been done so far.

The objective of the following study is therefore to systematically identify and quantify the concepts contained in health status measures in sleep medicine practice and research using the ICF as a reference. Specific aims are: (a) to compare measures used for different purposes in sleep medicine practice and research, (b) to examine the contents for items in the ICF; and (c) to deliver an evidence base for the international consensus process when developing a list of the most relevant ICF categories to describe any kind of primary sleep disorder.

METHODS:

ICF Core Sets process

This study is a preparatory study in the development of the ICF Core Sets for Sleep Disorders (33). The ICF Core Sets are lists of ICF categories selected for specific conditions, such as depression (34), obesity (35), and obstructive pulmonary disease (36) or for certain clinical settings, e.g. in vocational rehabilitation (37).

The ICF Core Sets for Sleep Disorders seek to capture the essential ICF functioning properties of any kind of primary sleep disorder as defined in the eight major diagnostic groups of the ICSD-2.

The process starts with evidence gathered through four preparatory studies followed by an international expert conference where consensus on a brief and a comprehensive version of the ICF Core Set is reached (38). One of these preparatory studies was to find out what researchers consider to be relevant, a systematic review of outcome measures in sleep medicine practice and research was conducted.

Design

A systematic literature review was conducted to identify and select questionnaires applied in sleep medicine practice and research.

A comprehensive search strategy for reviews, National/International Guidelines and Standard References, to ensure that all areas of functioning, disability and health were captured, was used. In order to gather the maximum amount of references a

three-way search strategy was employed using various degrees of quantitative and qualitative reach:

1. Review of Reviews: the literature databases MEDLINE, EMBASE, and PSYCINFO were systematically searched limiting the search to human adult studies, and reviews. The comprehensive search strategy employed which was targeting sleep-specific questionnaires used the following terms and their variants:

(Sleep*) or (Sleep in title or abstract)

<u>and</u>

(instrument*) or (measure) or (questionnaire) or (index) or (measurement) or (scale) or (inventory) or (classification) or (outcome) or (assessment).

An eligibility check was conducted screening the abstracts identified through the literature search. Reviews referring to aspects of sleep disorders and/or quality of life were included.

2. internet-based sources and standard references in sleep medicine practice and research for international guidelines, standard procedures and standard references describing the state-of-the-art of outcome measurement were screened.

3. We consulted expert opinion, used conference visits, and conducted reference-chaining to identify more measures.

All the full text articles that were identified from the above sources containing concrete measures related to sleep were retrieved. Other questionnaires were obtained by contacting the original authors.

Linking procedure

From the questions and items of the selected questionnaires, so-called "meaningful concepts" were identified and linked, by researchers trained in the taxonomy of the ICF, to the ICF components using established linking rules (39, 40). The ICF categories which had been linked to the concepts contained in the questionnaires provided the basis of the descriptive and content analysis.

If an item of a measure contained more than one concept, each concept was linked separately. For example, in item 8 of the Medical Outcome Study 36-item short form health survey (SF-36) (Figure 2) (41) 'During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)', the concept 'pain', 'work outside the home' and 'housework' are linked

to b280 sensation of pain, d859 work and employment, other specified and unspecified and d640 doing house work, respectively (42).

Figure 2: Linking procedure and example
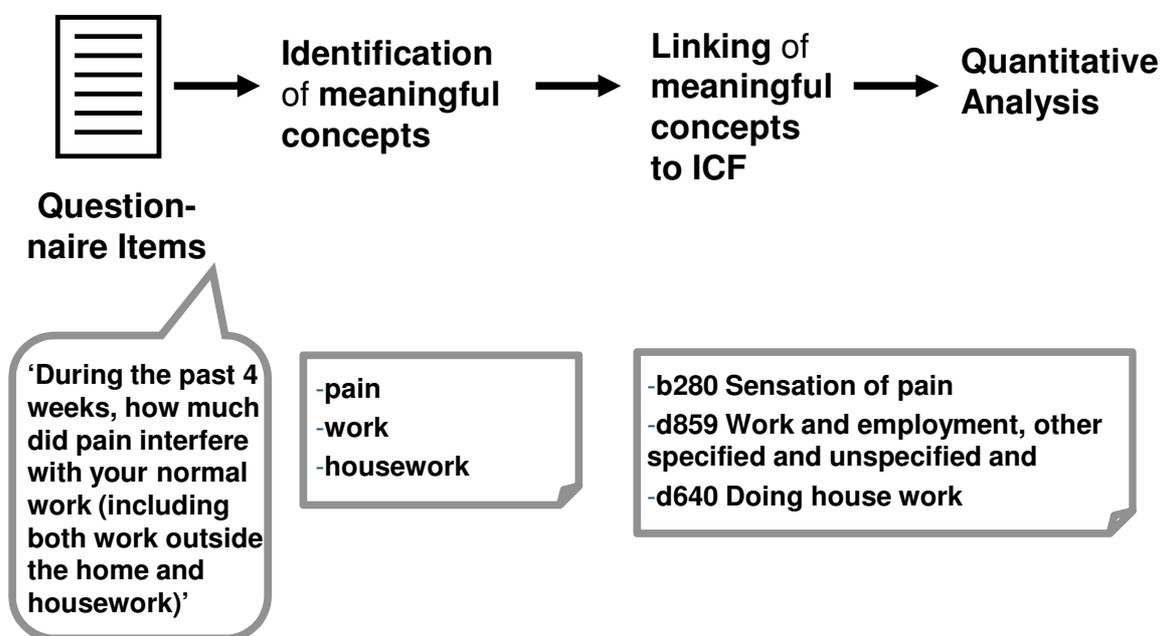
The linking procedure was performed separately by two health professionals experienced with the ICF. If an item or meaningful concept was too general to allow a decision on the linking to a specific ICF component, chapter, or category, the statement was considered as 'nd-not defined' (such concepts that are captured in ICF but not specific enough to be attributable to certain components or categories e.g. "limited daytime functioning"). If a statement described an aspect which is not covered by the ICF, the code 'nc-not covered' was attributed (e.g. "risk of accidents"). Items asking for information related to health conditions (e.g. comorbidities) were coded as 'hc-health condition'. The component 'personal factors' is not yet classified in the current version of ICF. Identified aspects of this component were therefore coded as 'pf'.

The analysis performed was qualitative and content-based on the level of wording and phrasing and is not a quantitative or psychometric study. No information was gathered on the level of severity ratings and scaling, the relationship between concepts and between items (e.g. no differentiation between 'sleepy and fatigued' and 'sleepy due to fatigue'), degrees of subjectivity within items (e.g. the difference

between 'How sleepy are you?' and 'Do you fall asleep during the day?'), or aspects of dimensionality. Thus, all concepts in items including additional information in itemizations or brackets were linked: e.g. 'interference with normal social activities with family, friends, neighbors, or groups?'.

Data analysis

For sake of a comprehensible display of the results the measures were broadly grouped and reported according to generalized purpose. The most common denominator that might help distinguishing the questionnaires is whether they are developed for or validated with persons with a certain health condition. Hence, we used the distinction between the different condition-specific instruments in order to report our results. The second broad discriminator might be that instruments seek to distinguish between health conditions or that they screen for the different manifestation properties (signs & symptoms). Hence, we used the distinction between generic type of questionnaires and symptom-related ones to further group our measures.

The frequencies of the outcome measures and the linked ICF categories were reported along with percentages, relative to the total number of concepts or the total number of measures. For the individual measures the number of ICF categories covered on the component level was calculated. In addition, the most frequently identified ICF categories in each ICF-component using the respective cut-offs of more than 20% for body functions, 15% for activities & participation, and 10% for environmental factors of measures were reported. If a concept was linked to a third- or fourth-level category, the corresponding second-level category was reported unless the third-level category was one of those included in b134 – sleep functions.

Content analysis

Based on the quantitative analysis of the linking-data we further report two content-related metrics developed by our group (43). Content density is a measure of multidimensionality within the item structure of a questionnaire. It is represented by a ratio calculated by dividing the number of concepts identified by the linking procedure by the number of items in each measure. Ratios close to one mean that each item contains one ICF concept while higher values show that, there are several concepts contained within each item.

The SF-36, for example, was found to have 54 concepts reflected in the 36 items giving us a content density ratio of 1.5 (43).

Content diversity is a measure of reach or bandwidth of a measure with regard to ICF categories or health-related aspects covered. It is calculated as a ratio using the number of 2nd level ICF categories divided by the number of linked meaningful concepts found during the linking process. Values close to one indicate that each meaningful concept of the measure corresponds to a different ICF category. Values closer to zero record lower content diversity, meaning that several concepts in the measure relate to one ICF category. In the SF-36, 23 different ICF categories were required in order to map the 54 concepts giving us a content diversity ratio of 0.43 (43).

The reliability of the linking process was evaluated by calculating unweighted kappa coefficients (44) and nonparametric bootstrapped confidence intervals based on the two independent linking versions of 50% of the overall number of measures. Kappa coefficients were calculated at the 2nd level of hierarchical ICF level to indicate the degree of agreement between the two health professionals conducting the linking procedure. The kappa analysis was performed with SAS (45).

RESULTS

The eligibility check on abstracts indicated 54 reviews. A total of 115 different patient-administered measures which could be extracted from the original articles or books, downloaded from the internet or received through direct contact with the original authors were identified and linked. Of these measures, 35 were of generic nature, 17 were symptom-related (eight sleepiness/six fatigue/two alertness/one tiredness), and 63 were condition-specific measures. The latter included 38 measures for Insomnia, 11 for Sleep Apnea, 10 for Restless Legs Syndrome, and 4 Narcolepsy questionnaires. Overall, the 4686 meaningful concepts contained in the items of all the sleep measures were linked to 133 different 2nd level ICF categories. The majority of these categories (61.4%) were linked to 54 different ICF categories of the ICF component body functions, followed by 15.3% of concepts linked to 49 different categories in activities & participation, and 9.8% of concepts linked to 22 categories in environmental factors. The component body structures were the least frequent (0.5%). Most concepts were assigned to ICF categories at the 2nd and 3rd levels (n=1787, 38.1% and n=2113, 45.1% respectively).

In addition, 175 (3.7%) concepts were linked to the ICF component, personal factors. Included under 'other', 227 concepts (4.8%) were linked as 'nc' [not classifiable, e.g. questions related to time], 108 (2.3%) of concepts as 'hc' [health condition, e.g. questions related to comorbidities], and 100 (2.1%) as 'nd' [not definable,].

All the questionnaires, their references, the groups according to general purpose and the range of ICF components covered by each measure and their purpose groups respectively are listed in the annex in Table 1. The table depicts the respective and overall content measures of density and diversity. Overall, one questionnaire item represented 1.8 meaningful concepts (density). On average, 2.5 concepts in the questionnaires represent one and the same ICF category (diversity).

The Brock Sleep and Insomnia Questionnaire BSQI (46) contains the highest (n=371) and the Nocturnal Sleep Onset Scale NSOS (47, 48) the lowest (n=2) number of meaningful concepts. The highest value (9.8) for content density was found in the Augmentation Severity Rating Scale ASRS (49), which has 4 items containing 39 concepts. It is lowest (1.0) for the Multidimensional Fatigue Symptom Inventory MFSI (50, 51), which has 83 items containing 84 concepts.

The content diversity ratio is highest (0.9) in the Tiredness Symptoms Scale TSS (52), where 12 different ICF categories have been used to map the 14 concepts. The content diversity ratio is lowest (0.33) for the Sleep Timing Questionnaire (53), where 2 different ICF categories were used to represent 21 concepts.

The relative frequencies of the number of measures mentioning the respective category above a certain cut-off, except for component body structures, where all identified 2nd level categories are reported, are shown in Figure 3. The most frequently identified category for body functions was 'sleep functions' (87.8%), for body structures 'structure of lower extremity' (4%), for activities and participation 'recreation and leisure' (32.7%) and for environmental factors 'products and substances for personal consumption' (33%).

Figure 3: Most frequently identified ICF Categories

ICF

Functioning and Disability

Body Functions and Body Structures

Component + Body Functions (codes b1-b8)		61.4
Chapter 1 Mental functions (b1)		
b110	Consciousness functions	29.6*
b126	Temperament and personality functions	40.9
b130	Energy and drive functions	57.4
b134	Sleep functions	87.8
3rd Level	b1340 Amount of sleep	40
3rd Level	b1341 Onset of sleep	64.3
3rd Level	b1342 Maintenance of sleep	53.9
3rd Level	b1343 Quality of sleep	66.1
3rd level	b1344 Functions involving the sleep cycle	21.7
b140	Attention functions	20
b147	Psychomotor functions	24.3
b152	Emotional functions	48.7
b160	Thought functions	28.7
Chapter 2 Sensory functions and pain (b2)		
b280	Sensations of pain	22.6
Chapter 4 Functions of the cardiovascular, haematological, Immunological and respiratory system (b4)		
b450	Additional respiratory functions	22.6
b460	Sensations associated with cardiovascular and respiratory functions	22.6
Chapter 7 Neuromusculoskeletal and movement-related functions (b7)		
b765	Involuntary movement functions	21.7

*2nd and 3rd level categories in Body Functions (Percentage of measures mentioning the respective ICF category; ≥20%)

Component + Body Structures (code s s1-s8)		0.5
Chapter 3 Structures involved in voice and speech (s3)		
s320	Structure of mouth	1*
s330	Structure of pharynx	1
Chapter 4 Structures of the cardiovascular, immunological and respiratory system (s4)		
s410	Structure of cardiovascular system	1
Chapter 7 Structures related to movement (s7)		
s710	Structure of head and neck region	2
s720	Structure of shoulder region	1
s730	Structure of upper extremity	2
s740	Structure of pelvic region	1
s750	Structure of lower extremity	4

*All 2nd level ICF Categories in Body Structures (Percentage of all measures (N=115) mentioning the respective ICF category)

Activities and Participation

Component + Activities & Participation (codes d1-d9)		15.3
Chapter 2 General tasks and demands (d2)		
d230	Carrying out daily routine	22*
Chapter 4 Mobility (d4)		
d415	Maintaining a body position	19.1
d475	Driving	16.5
Chapter 5 Self-care (d5)		
d570	Looking after one's health	20
Chapter 7 Interpersonal interactions and relationships (d7)		
d770	Intimate relationships	16.5
Chapter 8 Major life areas (d8)		
d850	Remunerative employment	28.7
d855	Non-remunerative employment	15.7
Chapter 9 Community, social and civic life (d9)		
d920	Recreation and leisure	32.2

*2nd level categories in Activities & Participation (Percentage of measures (N=115) mentioning the respective ICF category; ≥15%)

Contextual Factors

Environmental Factors

Component + Environmental Factors (codes e1-e5)		9.8
Chapter 1 Products and technology (e1)		
e110	Products or substances for personal consumption	33*
e115	Products and technology for personal use in daily living	9.6
Chapter 2 Natural environment and human-made changes to environment (e2)		
e240	Light	7.8
e245	Time-related changes	20
e250	Sound	21.7
Chapter 3 Support and relationships (e3)		
e310	Immediate family	11.3
Chapter 5 Services, systems and policies (e5)		
e580	Health services, systems and policies	8.7
e590	Labour and employment services, systems and policies	5.2

*2nd level categories in Environmental Factors (Percentage of measures (N=115) mentioning the respective ICF category; ≥5%)

Personal Factors

Component+ Personal Factors (not classified in ICF)	3.7

+Percentage of overall number of linked concepts on component level

The percentage of agreement between the independent linking of 58 out of the 115 (50.4%) questionnaires on the 2nd level hierarchy of the classification is 73.78%. After eliminating the amount of agreement expected by chance, the Kappa value is a substantial 0.71 (bootstrapped confidence interval: 0.69, 0.73).

Tables with the detailed linking results at all levels of the ICF's hierarchical system including the frequency of the ICF categories identified through the linking of each individual measure are available from the corresponding author.

DISCUSSION

This paper provides a comprehensive overview of currently used health status measures in sleep medicine research and practice using the ICF as an independent, external frame of reference. The resulting snapshot picture of the state-of-the-art in patient-administered outcome assessment related to sleep allows clear and precise access to central comparative information related to the measures assessed. The study is both comprehensive in the range of purpose groups covered and also in the application of a reference system that seeks to capture all aspects of health. In supplying both these perspectives, the results provide valuable information for the appropriate selection of measures for specific purposes and for the bio-psycho-social outlook of the field of sleep medicine as a whole.

It is evident by the predominance of body function category choices, that current measures mainly capture the biomedical manifestation properties of sleep disorders (signs & symptoms). Very few measures address body structures in the context of sleep disorders. When extending and combining this outlook towards functioning as defined by ICF these measures mainly look at the impact of the disorder on categories of activities and participation while some integrate the interaction of the above with person and environment.

The environmental factors are particularly interesting as they may appear as both a facilitator and a barrier to functioning in patients with a sleep disorder. While a snoring bed partner might put strain on the intimate relationship of a couple (54-56), the social support coming from an understanding partner might increase the successful treatment adherence to assisted ventilation (57-59), an intervention which might again improve relationships (60-62). Reciprocal relations also exist with the environmental factor drugs, both in its role as facilitator and barrier. It is also clear

that no one sleep-related questionnaire covers all the functioning concepts contained in the ICF.

Many of the outcome measures included in this analysis target specific sleep disorders and the factors most useful in diagnosing and managing that particular disorder. This is demonstrated by the large quantity of measures identified for RLS, where measurement development and use is often driven by the need of precisely declaring benefits and side-effects (e.g. in severity ratings, augmentation). This phenomenon would also explain why 'structure of lower limbs' was the most commonly seen body structure. Questionnaires for sleep apnea increase the number of 'respiratory functions' observed. The large number of measures within the insomnia group mainly represents categories of behavioral and mental functions (e.g. cognitions, arousal, sleep hygiene). Since activity limitations are furthermore often part of diagnostic procedures (63), the insomnia field offered the most comprehensive measures we reviewed.

Major new findings of this content analysis are related to content density and content diversity of the measures which partly answers the question of *how* we are currently measuring in the field of sleep medicine with respect to content. While it is evident that the measures might differ with respect to length and number of concepts contained, the indices of content density and diversity might still be helpful for the selection of the most efficient measures. Measures with lower levels of content density have less complex items which might be more applicable in clinical settings. Such measures were especially identified in the shorter formats of visual analog scales or diaries, or those questionnaires that assess symptoms. The higher the content density, the more complex the item, and the more difficulty patients are to have in understanding and answering those items. Items that measure more than one concept may also provide results which are more difficult to analyze correctly and the concept of content density may be used to assist in the analysis. Possibly the more dense questionnaires should be combined with less dense questionnaires in order to provide a broader spread of assessment.

The measure of content diversity might become useful when deliberating and balancing the number of items with the reach and bandwidth of content covered in relation to the ICF components and their health domains.

A lower index of content diversity indicates that several concepts and their items within the measure are dedicated to the same topic. Measures of sleep timing, sleep

cognitions or sleep hygiene are examples of measures with lower levels of content diversity. These measures might be more finely tuned and selective towards the topic they seek to explore. Those measures with a higher level of content diversity were encountered in such measures that look at the various consequences of disordered sleep on quality of life or activities and participation, and those intended for diagnostic or screening purposes, e.g. questionnaires looking at severity or symptoms.

It is important to note that the figures of content density and diversity are neutral and subsidiary indicators of the ICF-based contents included in the item structure of the respective measure. Low content density or diversity of a measure does not necessarily imply being a better or worse measure than another measure with higher content density or diversity. The purpose to which the measure is applied and how it behaves psychometrically determine the usefulness of the measure. The indices do however make the measures comparable with regard to ICF-based content covered.

Many of the questionnaires derive worth from the personal perspective of the patient and this focus seems especially important. This is further supported by our finding of 3.7% of concepts being linked to personal factors. It might be worth considering that these softer aspects of the subjective health experience might extend to other sleep-disordered patient groups, where other medical disorders which show insomnia or mental disorders as a frequent comorbidity are encountered (64-70). Treatment adherence to continuous positive airway pressures (CPAP) might be cited as a case in point with increasing evidence indicating the variability and complexity of this problem (71). The enhancement of multidisciplinary models with psychosocial interpretations may provide increased explanatory and interventional potential in models of CPAP use (72-75).

In a comprehensive bio-psycho-social framework such as ICF the above insights give an overview and an answer to the question of what we are currently measuring in sleep medicine research and practice. The overview provided by our study indicates the complexity of sleep medicine as a multidisciplinary and multidimensional field of assessment. The international consensus process of which this study is a part seeks to identify relevant categories of the ICF for persons with any kind of (primary) sleep disorder (38). The data collected here will serve as an evidence base for the concluding consensus conference. However, our evidence might be slightly tainted

since we did not encounter any questionnaires that explicitly assess the less prominent diagnostic groups (e.g. parasomnias like sleep-related eating disorders).

The resulting 'ICF Core Sets for Sleep Disorders' seeks to broaden what can be measured when looking to address patient's needs, resources and trajectories in a holistic and comprehensive way. Together with the evidence base and the item pool provided by this content analysis a first step to identify suitable existing measures or developing new measures has been taken (76).

Taking stock of what we are currently measuring and what must be considered the 'canon' was the aim of this study. To this end the application of a broad and open search strategy aimed to establish this through the unusual method of reviewing reviews. This means that the sample we identified necessarily contained some older measures that may not be in use any more and newer and more comprehensive measures already exist that we have not included as they have not reached the threshold of being reproduced through reviews and validation studies. Some recently published reviews were also not included for this analysis (77-79).

A further limitation alludes to the way this data was presented. In order to be concise, we were not able to represent the concrete analysis of each measure or purpose group in greater detail. We further had to represent the data on the component level or the 2nd level of hierarchy, omitting more detailed information that might have been of interest. Furthermore, it is debatable whether the ICF classification system, with its given categories and given levels of hierarchy, in itself can be considered as a suitable reference system since it must withstand the same criteria for content validity that we apply to other measures (80). A major limitation of ICF with regard to sleep medicine is the fact that 'the descriptions of health and health-related domains refer to their use at a given moment (i.e. as a snapshot)' ((15), p. 22). Accordingly, we were not able to code aspects of time-extensional measures that affect diagnosis, treatment, and functional assessment. ICF delivers a taxonomy or vocabulary but it lacks the grammar.

We are furthermore aware, that the linking rules applied for this analysis do not differentiate between concepts and context. One and the same concept was linked to the same ICF category regardless of which perspective was factored into the overall questionnaire or item structure. In order to resolve these methodological issues we are currently revising the linking procedure.

This whole exercise may be seen as an isolated strategy from WHO but this would be untrue. International expert groups of the Lancet Mental Health Group and the Child Health and Nutrition Research Initiative recently conducted an expert survey to identify research priorities for health in people with disabilities (81) and those affected by mental health problems (82).

Such endeavors give further impetus to discussion about and application of the ICF adding to the predominant linearization from the disease perspective an integrative and comprehensive perspective that looks at impact, functional problems and needs of people living with sleep disorders.

In conclusion, this analysis of 115 sleep-related questionnaires has extended the current knowledge regarding the relationship of concepts contained within these questionnaires to the ICF system of classification. Two new measures, content density and diversity, used in this analysis may be helpful in the future when clinicians decide on the specific questionnaire to be used.

Practice Points:

- ICF is a suitable internationally accepted, independent framework to analyze content of health status measures.

- ICF-based content metrics add an additional content estimate:

  1. Content density: measure of multidimensionality within the item structure of a questionnaire (number of concepts/number of items)

  2. Content diversity: measure of reach or bandwidth of an instrument (number of different 2nd level ICF categories/number of linked meaningful concepts)

- Overview table may help sleep clinicians/researchers to choose the appropriate instrument for specific interests or purposes.

Research Agenda:

- Extend prevailing biomedical focus to psychosocial, comprehensive and multi-directional approaches based on ICF.

- Establish the epidemiology of functioning in sleep disorders and using functioning as a common denominator in the field of sleep medicine.

- Systematically identify and use changes in functioning in patients with sleep disorders to sustainably address the patients' lived experiences.

- Develop tools and measures based on ICF that are comprehensive and feasible (international validation of ICF Core Sets for Sleep Disorders).

- Interrogate categories not currently covered as to their worth in assessing sleep disorders

ACKNOWLEDGEMENTS:

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Appendix: Table 1: Grouping of 115 measures including name and references, content metrics, ICF components covered, sources

[1] Content Density = (Number of linked concepts / Number of instrument items)
[2] Content Diversity = (Number of different 2nd level ICF categories used per instrument / Number of linked concepts)
[Comp. BF=ICF Component Body Functions; Comp. BS=ICF Component Body Structures; Comp. A&P=ICF Component Activities and Participation; Comp. EF=ICF Component Environmental Factors; nc=not covered; nd=not defined; hc=health condition; pf=personal factor; RLS=Restless Legs Syndrome; QoL=Quality of Life]

Group	Type of Instrument	Name of Instrument	Content Density [1]	Content Diversity [2]	No. of linked concepts: Comp. BF	No. of linked concepts: Comp. BS	No. of linked concepts: Comp. A&P	No. of linked concepts: Comp. EF	No. of linked concepts: nc, nd hc, pf	Source citing/re-viewing instru-ment
GENERIC	Generic	Jenkins Sleep Problems Scale (JSPS) (1)	1.8 (7/4)	0.3 (2/7)	7					(2-6)
	Generic	Sleep Effects Index (7)	1.1 (31/28)	0.4 (11/31)	25		6			(5, 6)
	Generic	John's Instrument (8)	2.2 (24/11)	0.1 (3/24)	12			6	6	(6, 9)
	Generic	Self-rated Sleep Questionnaire (SRSQ) (10, 11)	1.6 (29/18)	0.5 (14/29)	21	1	4	2	1	(2)
	Generic	Patient Reported Outcomes Measurement Information System (PROMIS) Item Bank v. 1.0 – Sleep Disturbance (12)	1.6 (42/27)	0.3 (11/42)	37		3		2	
	Generic	Patient Reported Outcomes Measurement Information System (PROMIS) Item Bank v. 1.0 – Wake Disturbance (12)	1.6 (26/16)	0.3 (7/26)	23		3			
	Generic	Previous Night Sleep Inventory (PNSI) (13)	1.2 (12/10)	0.3 (3/12)	12					
	Generic	Sleep Questionnaire SF-A (German) (14)	2.4 (55/23)	0.4 (20/55)	30		3	12	10	(3, 15)
	Generic	Sleep Questionnaire SF-B (German)	2.3 (66/29)	0.3 (23/66)	37		6	13	10	(3, 15)
	Generic	Sleep Disorders Inventory (SDI) (16)	1.8 (14/8)	0.4 (6/14)	12		1		1	
	Generic	Sleep Disorders Questionnaire	2 (350/175)	0.2 (72/350)	215	5	41	55	34	(5, 6)
	Generic (Behaviour)	Sleep Habits Questionnaire (Sleep Heart Health Study)(17)	2 (72/36)	0.4 (26/72)	50		13	8	1	
	Generic (Behaviour)	Sleep Behaviors Scale 60+ (18)	1.6 (48/30)	0.5 (24/48)	12		27	9		(3)
	Generic (Chronotype)	Self-Assessment Morningness-Eveningness Questionnaire (19, 20)	1.2 (22/19)	0.3 (7/22)	15		2		5	(3, 21, 22)
	Generic (Chronotype)	Munich Chronotype Questionnaire (MCTQ) (23, 24)	2.5 (70/28)	0.2 (12/70)	21		5	15	29	(25)
	Generic (Diagnostic)	Dutch Sleep Disorders Questionnaire (26)	1.8 (103/57)	0.3 (28/103)	78		11	4	10	(3, 6)

Generic (Diagnostic)	SLEEP-50 Questionnaire (27)	2.1 (104/50)	0.3 (30/104)	82	1	7	6	8	(5)
Generic (Diagnostic)	Pittsburgh Sleep Quality Index (PSQI)(28)	1.3 (30/24)	0.5 (16/30)	23		5	1	1	(2, 5, 6, 9, 22, 29-31)
Generic (Diary)	Evening - Morning Protocol (32)	2 (38/19)	0.4 (14/38)	25		1	5	7	(3, 33)
Generic (Diary)	Karolinska Sleep Diary (KSD)(34, 35)	1.1 (8/7)	0.3 (2/8)	8					(2-6)
Generic (Diary)	Sleep Timing Questionnaire (36)	1.2 (21/18)	0.1 (2/21)	3				18	(2, 5, 6)
Generic (Diary)	Pittsburgh Sleep Diary (37, 38)	1.8 (32/18)	0.4 (13/32)	21		2	7	2	(2, 4, 5, 22, 29)
Generic (Diary)	Sleep History Analysis (39)	2.1 (42/20)	0.4 (16/42)	29		5	7	1	(22)
Generic (Functioning)	Functional Outcomes of Sleep Questionnaire (FOSQ) (40)	1.4 (42/30)	0.5 (23/42)	13		29			(2, 29, 41-43)
Generic (Functioning)	Medical Outcome Study (MOS) Sleep Scale (44)	1.9 (23/12)	0.3 (6/23)	23					(2, 4)
Generic (QoL)	Hamburger Visual Analog Scale (45)	1.2 (14/12)	0.6 (8/14)	3		7		4	(46)
Generic (Quality of Sleep)	Leeds Sleep Evaluation Questionnaire(47)	3 (18/6)	0.4 (7/18)	14		1	3		(5, 6, 22, 48-50)
Generic (Quality of Sleep)	St. Mary's Hospital Sleep Questionnaire(51, 52)	1.4 (19/14)	0.3 (5/19)	18				1	(2-6, 22)
Generic (Quality of Sleep)	Sleep Questionnaire - Subjective Assessment(53)	1.4 (47/33)	0.1 (7/47)	41		1	1	4	(4, 22)
Generic (Quality of Sleep)	Verran and Snyder-Halpern Sleep Scale (VSH)(54)	1.1 (9/8)	0.2 (2/9)	9					(6)
Generic (Quality of Sleep)	Visual Analog Scale for Quality of Sleep Schneider (55)	1 (6/6)	0.2 (1/6)	6					(3)
Generic (Quality of Sleep)	Sleep Quality Index (SQI) (56)	1.3 (8/6)	0.3 (2/8)	7			1		(2)
Generic (Quality of Sleep)	Post Sleep Inventory (57)	1.3 (39/30)	0.4 (14/39)	33			3	3	(5, 6, 22)
Generic (Screening)	Global Sleep Assesment Questionnaire (58)	3.4 (37/11)	0.5 (18/37)	22		4	3	8	(5)
Generic (Sleep Hygiene)	Sleep Hygiene Questionnaire (39)	2.5 (25/10)	0.5 (13/25)	15		4	5	1	(22)
TOTAL (Generic)		**1.80 (1533/853)**	**Ø= 0.34**	**1002 65.3%**	**7 0.5%**	**191 12.5%**	**166 10.8%**	**167 10.9%**	
Insomnia	Insomnia Treatment Acceptability Scale (59)	2.6 (42/16)	0.2 (9/42)	10		6	15	11	
Insomnia	Espie Sleep Disturbance Questionnaire (ESDQ) (60)	1.6 (19/12)	0.6 (11/19)	12		6		1	(2-6, 22)
Insomnia	Sleep Dissatisfaction Questionnaire (61)	1.9 (57/30)	0.2 (14/57)	50		6		1	(2)

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Insomnia	Athens Insomnia Scale (AIS) (62, 63)	1 (8/8)	0.4 (3/8)	6				2	(3-6, 29)
Insomnia	Insomnia Severity Index (64, 65)	2.7 (19/7)	0.6 (12/19)	12		3		4	(5, 6, 22, 29, 59)
Insomnia	Kryger's subjective measurements (66)	1 (9/9)	0.2 (2/9)	9					(3)
Insomnia	Nocturnal Sleep Onset Scale NSOS (67, 68)	1 (2/2)	0.5 (1/2)	2					(3)
Insomnia	Pittsburgh Insomnia Rating Scale (PIRS) (69)	1.5 (97/65)	0.3 (27/97)	73		14	3	7	(3)
Insomnia	Hatoum's Questions (70)	1.9 (28/15)	0.4 (10/28)	26		2			(3)
Insomnia	Insomnia Interview Schedule (59)	2.2 (124/56)	0.3 (34/124)	75		14	21	14	(22)
Insomnia	Wolff's Morning Questions (71)	1.3 (8/6)	0.5 (4/8)	5			2	1	(3)
Insomnia	Leger's Q1 Questionnaire (72)	2.5 (10/4)	0.5 (5/10)	10					(3)
Insomnia	SleepMed Insomnia Index (SMII) (73)	2.2 (20/9)	0.4 (7/20)	15			3	2	
Insomnia	Brock Sleep and Insomnia Questionnaire (BSIQ) (74)	2.6 (371/141)	0.1 (42/371)	136		26	91	118	(22)
Insomnia	Lacks Sleep History Questionnaire (75)	1.6 (78/48)	0.3 (26/78)	49		4	17	8	(3, 22)
Insomnia (Arousal)	Pre-Sleep Arousal Scale (PSAS) (76)	1.6 (25/16)	0.6 (15/25)	23		1	1		(3-5, 22, 29)
Insomnia (Arousal)	Regestein's Hyperarousal Scale (77, 78)	1.3 (33/26)	0.5 (15/33)	18		3	7	5	(29)
Insomnia (Arousal)	Arousal Predisposition Scale (79, 80)	1.3 (16/12)	0.4 (7/16)	12		1		3	(22, 29)
Insomnia (Behaviour)	Sleep Behavior Self Rating Scale (81, 82)	1.7 (33/20)	0.4 (13/33)	17		15	1		(3, 5, 22)
Insomnia (Cognitions)	Sleep Cognitions Questionnaire (FB-SK) (83)	1 (45/43)	0.2 (10/45)	33		3	2	7	(3)
Insomnia (Cognitions)	Dysfunctional Beliefs and Attitudes about Sleep Scale (DBAS) (84-87)	2.5 (71/28)	0.2 (12/71)	47		5	3	16	(2-6, 22, 29)
Insomnia (Cognitions)	Sleep Beliefs Questionnaire (88-90)	2.2 (89/40)	0.3 (28/89)	64		13	4	8	(9)
Insomnia (Cognitions)	Beliefs and Attitudes Questionnaire (39)	2.6 (26/10)	0.3 (9/26)	16		4		6	
Insomnia (Cognitions)	Sleep Anxiety Scale (91)	1.5 (12/8)	0.3 (3/12)	10			2		(92)
Insomnia (Cognitions)	Glasgow Content of Thoughts Inventory (GCTI) (93)	1.3 (32/25)	0.5 (15/32)	18		3	2	9	(5)
Insomnia (Cognitions)	Sleep Beliefs Scale (94)	2 (39/20)	0.3 (11/39)	14		14	7	4	(5)
Insomnia (Diary)	Lacks Insomnia Interview (75)	1.2 (12/10)	0.3 (4/12)	11				1	(3, 22)
Insomnia (Diary)	Morin's Sleep Diary (59)	1.1 (11/10)	0.2 (2/11)	9			2		(5, 22)
Insomnia (QoL)	Quality of Life and Insomnia Questionnaire (95)	2.6 (179/68)	0.2 (31/179)	102		37	11	29	(9)

Insomnia (QoL)	Hotel Dieu 16 (HD-16) (96)	1.6 (25/16)	0.6 (15/25)	17		5		3	(29)
Insomnia (QoL)	Quality of Life of Insomniacs Questionnaire (QOLI) (97, 98)	1.2 (70/59)	0.3 (23/70)	51		9	3	7	(2, 3, 29)
Insomnia (Screening)	Insomnia Screening Chevalier (99)	2 (8/4)	0.5 (4/8)	7				1	(3)
Insomnia (Screening)	Short Insomnia Questionnaire (100)	1.6 (36/23)	0.4 (14/36)	23		5	2	6	(5)
Insomnia (Sleep Hygiene)	Sleep Hygiene Awareness and Practice Scale (SHAPS) (75, 101)	2.8 (65/23)	0.1 (9/65)	50		7	8		(3-5, 29)
Insomnia (Stress)	Ford Insomnia Response to Stress Test (FIRST) (102)	1.4 (13/9)	0.8 (11/13)	2		9		2	(29)
Insomnia (Symptoms)	Angst's Questions (103, 104)	1.7 (17/10)	0.4 (6/17)	14		3			(3)
Insomnia (Symptoms)	Spielman's Insomnia Symptoms Questionnaire (SISQ) (105)	1.2 (15/13)	0.3 (5/15)	15					(3-5, 22, 29)
Insomnia (Symptoms)	Minimal Insomnia Symptom Scale (MISS) (106)	1 (3/3)	0.3 (1/3)	3					
TOTAL (Insomnia)		**1.9 (1767/924)**	**Ø=0.37**	**1066 60.3%**	**0**	**218 12.4%**	**207 11.7%**	**276 15.6%**	
NARCOLEPSY Narcolepsy	Ullanlinna Narcolepsy Scale (107)	1.7 (19/11)	0.4 (8/19)	14		4		1	
Narcolepsy	Sleep Propensity in Active Situations (SPAS) (108)	1.4 (7/5)	0.4 (3/7)	5				2	
Narcolepsy	Stanford Center for Narcolepsy Sleep Inventory (109)	2(101/51)	0.2 (20/101)	91		5	2	3	
Narcolepsy (QoL)	Psychosocial Impact of Narcolepsy(110)	1.1 (19/18)	0.6 (11/19)	2		16	1		
TOTAL (Narcolepsy)		**1.7 (146/85)**	**Ø=0.4**	**112 76.7%**	**0**	**25 17.1%**	**3 2.1%**	**6 4.1%**	
RESTLESS LEGS SYNDROME RLS (Augmentation)	Structured Interview for Diagnosis of Augmentation (SIDA) (111)	2.8 (37/13)	0.2 (8/37)	9	1		12	15	(112)
RLS (Augmentation)	Augmentation Severity Rating Scale (ASRS) (113)	9.8 (39/4)	0.4 (14/39)	7	9	10	9	4	(112, 113)
RLS (Diagnostic)	Restless Legs Syndrome Diagnostic Index (RLS-DI) (114, 115)	1.2 (11/9)	0.8 (9/11)	5			3	3	(112)
RLS (QoL)	Restless Legs Syndrome Quality of Life Instrument (RLS-QLI)(116)	2.5 (43/17)	0.5 (20/43)	23		15	2	3	(112)
RLS (QoL)	Restless Legs Syndrome Quality of Life questionnaire (RLS QoL) (117)	2.9 (53/18)	0.4 (20/53)	18		27	2	6	(112)
RLS (QoL)	Restless Legs Syndrome Quality of Life Questionnaire(Kohnen) (118, 119)	1.9 (23/12)	0.4 (9/23)	13		5	1	4	(112, 120)
RLS (Severity)	RLS-6 Scale (121, 122)	2.3 (14/6)	0.5 (7/14)	9		5			(112)
RLS (Severity)	International Restless Legs Severity Rating Scale (IRLS)(123, 124)	1.5 (15/10)	0.7 (10/15)	3		6		6	(120, 125,

									126)
RLS (Severity)	Severity Scale of RLS (German) (127)	3.2 (32/10)	0.5 (16/32)	19	2	8		3	(128)
RLS (Severity)	Johns Hopkins Restless Legs Severity Scale (JHRLSS) (129, 130)	3 (9/3)	0.6 (5/9)	4			3	2	(125)
TOTAL (RLS)		**2.7 (276/102)**	**Ø=0.5**	**110 39.9%**	**12 4.3%**	**76 27.5%**	**32 11.6%**	**46 16.7%**	
Sleep Apnea	Multivariable Apnea Risk Index (MAP) (131-133)	2 (6/3)	0.5 (3/6)	6					(42)
Sleep Apnea	Berlin Questionnaire (134-137)	1.6 (16/10)	0.3 (4/16)	4			5	7	(138)
Sleep Apnea	Wisconsin Sleep Questionnaire (139, 140)	2.4 (112/46)	0.2 (27/112)	49		8	20	35	(6)
Sleep Apnea	Obstructive Sleep Apnea Patient-Oriented Severity Index (OSAPOSI) (141)	1.5 (48/32)	0.5 (23/48)	23		16	1	8	(43)
Sleep Apnea (QoL)	The Calgary Sleep Apnea Quality Of Life Index (SAQLI) (142, 143)	1.5 (133/88)	0.3 (40/133)	78	1	34	9	11	(6, 42, 43, 144)
Sleep Apnea (QoL)	Pulmonary Functional Status Scale (PFSS)(145-147)	1.9 (37/19)	0.4 (13/37)	24		13			
Sleep Apnea (QoL)	Quebec Sleep Questionnaire (QSQ)(148, 149)	1.7 (53/32)	0.4 (21/53)	39		13		1	(41, 43)
Sleep Apnea (Screening)	STOP Questionnaire (150)	2.1 (17/8)	0.7 (12/17)	9			4	4	
Sleep Apnea (Symptoms)	Basic Nordic Sleep Questionnaire (BNSQ)(151)	1.1 (18/19)	0.4 (7/18)	16		2	1		(2, 6)
Sleep Apnea (Symptoms)	Sleep Apnea/Hypopnea Syndrome (SAHS) related symptoms questionnaire(152, 153)	1.7 (25/15)	0.4 (11/25)	21		2	2		
Sleep Apnea (Symptoms)	Sleep-Symptom Questionnaire (154)	2.2 (35/16)	0.3 (12/35)	18		10	4	3	(42)
TOTAL (Sleep Apnea)		**1.7 (501/296)**	**Ø=0.4**	**287 57.3%**	**1 0.2%**	**98 19.5%**	**46 9.2%**	**69 13.8%**	
Symptom Alertness	Toronto Hospital Alertness Text (155, 156)	1.2 (12/10)	0.8 (9/12)	9		2		1	(144)
Symptom Alertness	ZOGIM-A Alertness Scale (155, 156)	1.7 (17/10)	0.6 (10/17)	9		3	3	2	(144)
Symptom Fatigue	Dutch Exertion Fatigue Scale (DEFS)(157)	1.1 (10/9)	0.7 (7/10)	1		9			
Symptom Fatigue	Multidimensional Fatigue Inventory (MFI-20)(158-161)	1 (20/20)	0.3 (5/20)	15		1		4	(29)
Symptom Fatigue	Brief Fatigue Inventory (BFI) (162, 163)	1.4 (13/9)	0.5 (6/13)	7		5		1	(164)
Symptom Fatigue	Dutch Fatigue Scale (DUFS)(157)	1.3 (12/9)	0.5 (6/12)	9		3			
Symptom Fatigue	Multidimensional Fatigue Symptom Inventory (MFSI)(165, 166)	1 (84/83)	0.3 (26/84)	65	1	9	1	8	(164)
Symptom Fatigue	Fatigue Severity Scale (FSS) (167)	2.2 (20/9)	0.4 (8/20)	10		6		4	(29)
Symptom Sleepiness	Sleep-Wake Activity Inventory (SWAI)(68, 168, 169)	1.3 (78/59)	0.3 (20/78)	39		19		20	(2, 3, 5, 6, 42, 170,

The left margin carries the vertical section labels **SLEEP APNEA** and **SYMPTOMS**.

									171)
Symptom Sleepiness	Epworth Sleepiness Scale (ESS)(172, 173)	1.5 (12/8)	0.8 (9/12)	1		9	1	1	(2, 3, 5, 6, 29, 31, 42, 144, 171, 174)
Symptom Sleepiness	Rotterdam Daytime Sleepiness Scale (175)	1.5 (24/16)	0.5 (13/24)	9		14	1		(42)
Symptom Sleepiness	Resistance to Sleepiness Scale (176)	2.1 (25/12)	0.6 (14/25)	1		20	1	3	(2, 29)
Symptom Sleepiness	Stanford Sleepiness Scale (177)	3.4 (24/7)	0.3 (7/24)	22		1		1	(2, 3, 5, 29, 31, 42, 144, 171)
Symptom Sleepiness	Daytime Sleepiness Scale (67, 68)	2.1 (17/8)	0.5 (9/17)	9		8			(3)
Symptom Sleepiness	Karolinska Sleepiness Scale (178, 179)	1.6 (8/5)	0.3 (2/8)	8					(42, 171)
Symptom Sleepiness/Fatigue	FACES of fatigue and sleepiness adjective checklist (180)	1.5 (73/50)	0.1 (9/73)	73					(3, 29)
Symptom Tiredness	Tiredness Symptoms Scale (TSS) (181)	1 (14/14)	0.9 (12/14)	12		1		1	(167, 182)
TOTAL (Symptoms)		**1.4 (463/342)**	**Ø=0.49**	**299 64.6%**	**1 0.2%**	**110 23.8%**	**7 1.5%**	**46 9.9%**	
TOTAL OVERALL		**1.8 4686/2602**	**Ø=0.39**	**2876 61.4%**	**21 0.5%**	**718 15.3%**	**461 9.8%**	**610 13%**	

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Additional Information to be posted on Journal Website:
Item Pools with Linking Examples for selected ICF categories (Meaningful concepts in bold letters -
        only those that were linked to the ICF category in question)

ICF Category (Component Body Functions):
► **b126 Temperament and personality functions** *(Extraversion, Agreeableness, Conscientiousness, Psychic stability, Openness to experience, Optimism, Confidence, Trustworthiness)*
- Difficulty **getting along** with other people (PIRS)
- **feeling withdrawn, not feeling talkative, antagonistic** (SEI, VAS18)
- How often have you been feeling **impatient / that you are being unreasonable?** (SAQLI)
- Do you feel **touchy**? (DFQ)
- I **yelll at others**. (MFSI)
- Your **ability to get things done,** compared to your best. (PIRS)
- I am a **carfeul worker;** I am **good at details**; I am **overly conscientous** (Reg Hyp Scale)
- feeling **irritable / moody / short-tempered**; tendency to become **angry** (SAQLI/RLS QLI)
- My **temper** is **fiery** and **hard to control**; I get **impatient** easily (SWAI)
- I have **no interest** in daily occupations (Sleep50)
- Do not **care** about anything; I felt **downhearted and blue;** feeling **discouraged, hopeless** (QOL Insomnia)
- I am **uncertain** about things (MFSI)

ICF Category (Component Activities & Participation:
► **d230 Carrying out daily routine** *(Managing daily routine, Completing the daily routine, Managing one's own activity level)*
- Do you have **difficulty getting things done** because you are too sleepy or tired (FOSQ)
- How often have you **adjusted your** schedule to avoid this activity (SAQLI)
- Are you still capable recently of carrying out **routine everday activities**? (Dutch Fatigue Scale)
- How often have you been feeling like you were **unable to cope with everyday issues**? (SAQLI)
- Feeling that **ordinary activities require an extra effort** to perform or complete? (Quebec)
- How often does a lack of alertness affect **your normal daytime activities**? (RLS-QLI)
- I have a lot of **control over my schedule**. (SWAI)
- I need help **doing my usual activities**. (MFSI)
- In the past 4 weeks how much did your restless legs disturb your **ability to carry out your daily activities** (QoL Q RLS)
- Have you had any of the following problems with **regular daily activities** (QOL Insomn)
- Interference with **daily tasks**: "During the last month, to what extend has sleepiness interfered with your life?" (Kump)
- I can't get my sleep pattern into a **proper routine** (ESDQ, Sleep DissQ)
- I experience **difficulties finishing something I've started (**HD16)
- ability to **function daily chores** (ISI)
- My **routine** is predictable (Reg Hyp Ar Sc)
- What is your **prebedtime routine** like? (Ins Int Sched)
- I have no pleasure or interest in **daily occupations**. (Sleep50)

ICF Category (Component Environemental Factors):
► **e250 Sound** *(Sound intensity, Sound quality)*
- Have your sleep disturbed by **noise** (SHAPS)
- It is **too noisy in my bedroom** during the night. (Sleep 50)
- awakened by: **Noise** in your surroundings. (Sleep habits Q)
- schlecht geschlafen: **Geräusche / Lärm** (Abend Morgen Prot)
- Snoring intensitiy: About as **loud** as mumbling or talking / **louder than talking** (Kump)
- Sensations (**like noises**, hot or cold, pain) during the night (PIRS)
- **Irritation with sounds**, sights, or sensations during the day (PIRS)
- Bright lights, crowds, **noises or traffic bother me**. (Reg Hyp Ar Scale)
- A **sudden loud noise** would cause me a prolonged reaction. (Reg Hyp Ar Scale)
- Being distracted by **sounds, noise** in the environment (e.g. **ticking of clock, house noises, traffic**) (Pre Sleep Ar Scale)
- Snoring **loudly a**nd bothering others (Dutch SDQ)
- What wakes you up at night? (circle any that apply) pain, **noise**, nocturia, child, spontaneous (Insomn Int Sched)
- Is your bedroom **quiet**? (Insomn Int Sched)
- How often is your sleep disturbed by **environmental factors** such as **traffic**, neighbors, or family members? (Lacks Sleep Hist Q)
- awakened by: (check one) alarm clock/radio; someone whom I asked to wake me; **noises**; just woke (Pittsb Sleep Diary)

Identification of problems in functioning of persons with sleep disorders in a clinical setting using the International Classification of Functioning Disability and Health (ICF)-Checklist

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Summary

We conducted an explorative, cross-sectional, multi-centre study in order to identify the most common problems of persons with any kind of (primary) sleep disorder in a clinical setting using the International Classification of Functioning, Disability and Health (ICF) as a frame of reference. Data was collected through a structured face-to-face Interview with patients of 45-60 mins. A case record form for health professionals containing the extended ICF Checklist, socio-demographic variables, and disease specific variables was used. The study centres collected data of 99 individuals with sleep disorders. The identified categories include 48 (32%) for body functions, 13 (9%) body structures, 55 (37%) activities and participation and 32 (22%) for environmental factors. 'sleep functions' (100%) and respectively 'energy and drive functions' (85%) were the most severely impaired 2nd level categories of body functions followed by 'attention functions' (78%) and 'temperament and personality functions' (77%). With regard to the component activities and participation patients felt most restricted in the categories of 'watching' [e.g. TV](82%), 'recreation and leisure' (75%) and 'carrying out daily routine' (74%). Within the component environmental factors the categories 'support of immediate family', 'health services, systems and policies' and 'products or substances for personal consumption [medication]' were the most important facilitators; 'time-related changes', 'light' and 'climate' were the most important barriers. The study identified a large variety of functional problems reflecting the complexity of sleep disorders. The ICF has potential to provide a comprehensive framework for the description of functional health in individuals with sleep disorders in a clinical setting.

INTRODUCTION

Sleep medicine is an inherently multidisciplinary and complex field (Pevernagie et al., 2009). It comprises neurological, pneumological, physiological, behavioral, and psychosocial aspects. Among the common denominators of the over 80 different diagnoses specified in the International Classification of Sleep Disorders (AASM, 2005), is some form of daytime manifestation of the underlying sleep disturbance.

Involuntary naps, sleep attacks and drowsiness are hallmarks of excessive daytime sleepiness (EDS), a consequence common to the vast majority of patients with a sleep disorder (Engleman and Douglas, 2004, Thorpy, 2005, Guilleminault and Brooks, 2001).

However, not only the signs and symptoms as specified in the International Classification of Diseases (ICD-10th revision)(WHO, 2007) are relevant when sleep disorders are described but also how they manifest in the lived experience of persons with sleep disorders. We know that sleep disorders also extend to health-related aspects of this lived experience. Especially, poor performance at work or school, disruption of family life, and frequent accidents (Colten and Altevogt, 2006) and the impact of these consequences on quality of life (Verster et al., 2008), the work environment, economy and health care expenditure are considerable (Hillman et al., 2006, Wittmann and Rodenstein, 2004, Reinhold et al., 2009).

The recognition of the importance of systematically assessing symptoms, functional limitations and quality of life to optimize the management of patients with sleep disorders is increasingly influencing the clinical practice and research in the field of sleep medicine (ATS/ASA 1998, Morgenthaler et al., 2007a, Morgenthaler et al., 2007b, AASM, 1999, Chesson et al., 1999a, Chesson et al., 1999b, Morin et al., 1999, NHLBI , 2003). Irrespective of the clinical context and the health-care situation in which sleep disorders manifest, an in-depth understanding, systematic consideration and solid description of the whole range of functional problems associated with sleep disorders are necessary.

The classification systems relevant to sleep medicine like the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)(APA, 1994) and the ICSD-2 seek to give credit to the important impact on a person's daytime functioning.

Both classifications use operational and broad definitions of functional manifestations as diagnostic criteria of the health conditions they seek to capture. Looking at insomnia as an example, the DSM-V uses the expression of 'causing significant

distress or daytime impairments in social, occupational or other sectors of daily life' without further specification, whereas ICSD-2 captures the functioning properties and essential criteria of insomnia in nine different 'forms of daytime impairment'. Not surprisingly, when comparatively applying these different classifications systems significantly varying prevalence rates are generated, as was shown in the recently conducted American Insomnia Survey (Kessler et al., 2009).

The International Classification of Functioning, Disability and Health (ICF)(WHO, 2001) fills this evident explanatory gap by offering a globally agreed-on framework for a more detailed and comprehensive description of the components of health and health-related states. It thereby complements classification systems like the ICD-10 or the ones mentioned above. The ICF framework is based on a bio-psycho-social model of health and provides added value to the conceptualisation of quality of life by including codes for the component environmental factors (Cieza et al., 2008).

So far, ICF based assessment instruments like the ICF Checklist or the WHO Disability Assessment Schedule II (WHO DAS II)(WHO, 2010) have scarcely been used in sleep research. Furthermore, the ICF is a highly comprehensive classification containing more than 1400 categories to describe patient's functioning, disability, and health. This comprehensiveness is a major advantage and strength of the ICF. But at the same time it is the major challenge to its practicability and feasibility. Therefore tools such as ICF Core Sets are needed to enhance its practicability (Ustun et al., 2004, Stucki et al., 2008b). ICF Core Sets for Sleep Disorders are currently being developed. They are selections of ICF categories which capture those aspects of functioning that are most likely to be affected in persons with sleep disorders (Stucki et al., 2008a). With this project we seek to answer the question about the essence of functioning in the lived experience of persons with any kind of sleep disorder. In order to create a preliminary evidence base for the international consensus process, we conducted four pilot studies exploring four different perspectives on sleep disorders (expert/researcher/patient/clinical perspective).

The objective of this descriptive study is therefore to explore the lived experience of patients with any kind of sleep disorders with regard to functioning, disability and health in a clinical setting.

MATERIALS AND METHODS

Study design

This is a cross-sectional, multi-centre study utilizing health professional-rated structured interviews.

Sample

A convenience sample of patients was consecutively recruited in the sleep centres of the University clinics of Berne and Zurich and the Clinic Barmelweid (all Switzerland), each in different Swiss cantons (provinces).

In order to obtain a comprehensive picture of the whole continuum of clinical care (maximum clinical variation), patients of any etiopathology (first contact, control visits, and chronic) were included.

Individuals were included; (1) if they had a diagnosis of a primary sleep disorder according to the 2nd edition of the International Classification of Sleep Disorders, (2) if they were older than 18 years of age, (3) if they spoke the German language, (4) if they had been attested to be sane (compos mentis) and capable of making decisions by discretion of the investigator/health professional, (5) if they had been informed of the purpose and reason of the study, and both had been understood, (6) if they had signed the patient consent form. Individuals with significant cognitive impairment or the main diagnosis of a major psychiatric disorder were excluded.

The study was approved by the ethics committees in charge of the respective study centres involved (Records for Berne: 279/07; Zurich: E-37/2008; Aargau: 2008/064) and was performed in accordance with the Declaration of Helsinki.

Measures

The health professional collected data through a health professional-rated structured interview based on the German version of the ICF Checklist of the WHO (Version 2.1a) (WHO, 2001).

The ICF Checklist provides a list with a total number of 128 first and second level ICF categories of the classification. Since the ICF Checklist is a generic template for a structured interview we extended this list with ICF categories that are specific for sleep medicine. To this end we conducted a systematic review and content analysis of existing sleep questionnaires (Gradinger et al., 2008). Two researchers (multiple coding)

independently linked the questionnaire items to categories of the ICF based on established linking rules (Cieza et al., 2002, Cieza et al., 2005) and a list of sleep specific linking rules. These sleep-specific linking rules comprise a preceding list of agreed-on conventions about which ICF category definitions best capture and where to assign leading signs and symptoms of sleep disorders: e.g. tiredness=b130; sleepiness=b1343; apnoea=b440; snoring=b450; fatigue=b455; d570=sleep hygiene. The concrete procedures are published elsewhere; specific data can be obtained from the corresponding author and ICF codes can be browsed on: http://apps.who.int/classifications/icfbrowser/.

Based on the content analysis of existing sleep measures, we selected categories that were not covered in the original ICF Checklist if they were mentioned and identified in at least two different sleep-specific questionnaires. Figure one gives an example of the procedure for the extension category b126 Temperament and personality functions.

Figure 1: Linking procedure and example for extension of ICF Checklist
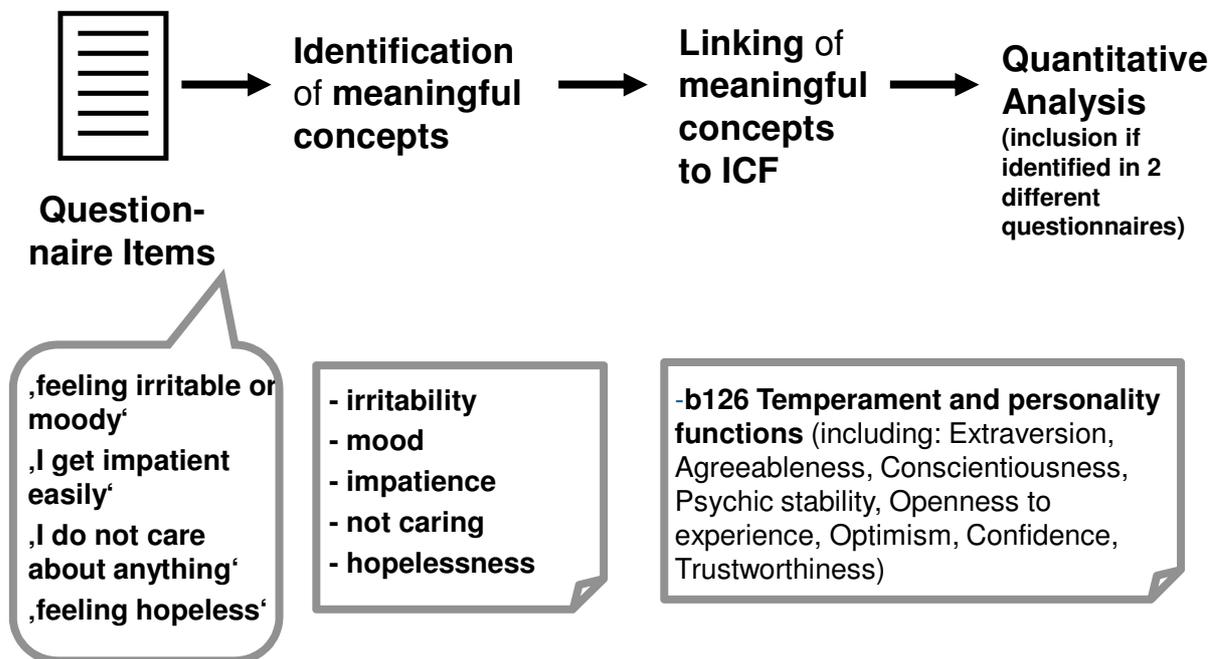
The ICF Checklist 2.1a was complemented with 34 2nd level ICF categories so that the final questionnaire contained 162 categories. Included under these extension categories are the 5 specific sleep functions on lower hierarchical level of the ICF (b1340 Amount of

sleep, b1341 Onset of sleep, b1342 Maintenance of sleep, b1343 Quality of sleep, b1344 Functions involving the sleep cycle).

The presence of the problem was denoted for each category of the components Body Functions, Body Structures and Activities and Participation using the ICF qualifiers 0 for 'no impairment/limitation', 1 for 'mild impairment/limitation', 2 for 'moderate impairment/limitation', 3 for 'severe impairment', and 4 for 'complete impairment'. The categories of the component Environmental Factors were graded with 0 for 'No facilitator and no barrier', +1/-1 for 'mild facilitator/barrier', +2/–2 for 'moderate facilitator/barrier', +3/-3 for 'substantial facilitator/severe barrier', and +4/-4 for 'complete facilitator/barrier'. Additionally, the qualifier '8' was used if the available information was not sufficient and '9' if the category was not applicable. Problems due to a comorbidity that was not associated with the sleep disorder were coded as described above and assigned with the code comorbidity (c).

The rating of each ICF category was estimated at the discretion of the interviewer in interaction with the respondent by reading out the name, definition and inclusion criteria of each category and giving examples. This estimation included the direct response of the interviewee, observations made by the interviewer during the interview and the consultation of medical records.

The health professionals entered collected data in an electronic database (Access).

Data analysis

For the ICF categories assigned to the components Body Functions, Body Structures and Activities and Participation relative frequencies (prevalence) of rater coding of impairment/limitation in the study sample are reported. For ease of access to the information we introduced meaningful and representative cut-offs for the report of the different components. For ICF categories representing Environmental Factors relative frequencies (prevalence) of people who regarded a specific category as either barrier or facilitator or both are reported. Missing values as well as the response options 'not applicable', 'not definable' and 'comorbidity' are not taken into account.

RESULTS

Using the Extended ICF Checklist, the data of 99 persons with any kind of primary sleep disorder were collected.

Sample:

The sample characteristics are shown in table 1.

Table 1: Sample Characteristics

Diagnostic groups	Overall (Stand. Dev.)	Insomnia	Sleep Related Breathing Disorders	Hyper-somnias of Central Origin	Circ-adian Rhythm Sleep Dis-orders	Parasomnias	Sleep Related Movement Disorders	Multiple Sleep Diagnosis
N	99	11	32	15	3	4	14	20
Age (years)	49,90 (±14.9)	49.92 (±16.3)	53.42 (±13.9)	41.33 (±15.7)	44.93 (±11.3)	39.33 (±20.2)	53.37 (±14.1)	51.11 (±13.6)
Gender (Female)	29	3	4	6	1	2	8	5

Figures 2-5 show the proportional distribution of ICF qualifiers over the most frequently impaired ICF categories. The identified categories include 48 (32%) for Body Functions, 13 (9%) Body Structures, 55 (37%) Activities and Participation and 32 (22%) for Environmental Factors.

Body Functions

Predominantly, b134 Sleep functions (98%) and the respective subcategories b1343 Quality of sleep [referring to non-restorative sleep, i.e. sleepiness] (94%), b1340 Amount of sleep (78%), b1342 Maintenance of sleep (75%), b1344 Functions involving the sleep cycle [referring to mental functions involved in rapid and non-rapid eye movement sleep](51%), b1341 Onset of sleep (42%) were impaired. Equally important were other categories of the chapter 1: Mental functions like b130 Energy and drive functions [referring to tiredness] (85%), followed by b140 Attention functions (78%) and b126 Temperament and personality functions (77%).

Figure 2: Prevalence of impairment in the ICF categories of the component 'body functions'. Graphs present the proportional distribution of ICF qualifiers relevant to over 50% of the sample (cut-off for reporting)


*Extension categories to ICF Checklist based on linking of outcome measures in sleep medicine
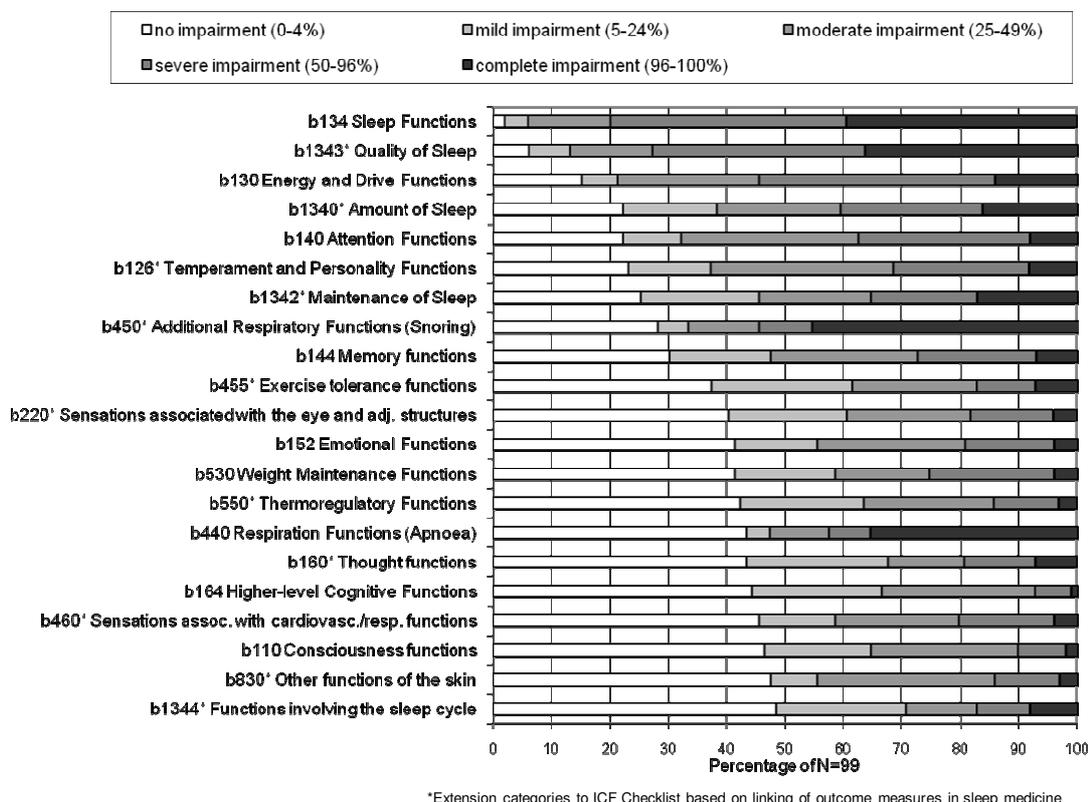
The categories related to the ICF chapter 4: b450 Additional respiratory functions [which refers to snoring] (72%), b455 Exercise tolerance functions [which refers to fatigue] (63%), b440 Respiration functions (57%), and b460 Sensations associated with the cardiovascular and respiratory functions [which refers to palpitations, shortness of breath etc.] (55%) were found to be at least mildly impaired by more than 50% of the sample.

Body Structures

Within the component body structures, s430 Structure of the respiratory system (53%), s410 Structure of the cardiovascular system (30%) were impaired in up to half of the patients. The categories s320 Structure of mouth (19%) and s110 Structure of brain (15%) were also commonly reported.

Figure 3: Prevalence of impairment in the ICF categories of the component 'Body Structures'. Graphs present the proportional distribution of ICF qualifiers relevant to at least 10% of the sample (cut-off for reporting)
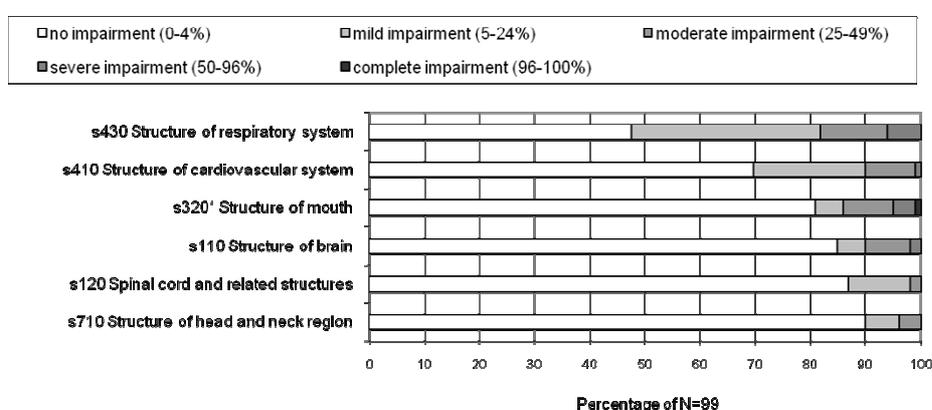
*Extension categories to ICF Checklist based on linking of outcome measures in sleep medicine

Activities and Participation

With regard to the component activities and participation patients felt most restricted in the categories of d110 Watching (82%), d920 Recreation and leisure (75%) and d230 Carrying out daily routine (74%). Relevant categories in the chapter 4: Mobility were d470 Using transportation [as a passenger] (70%), d415 Maintaining a body position [e.g. maintaining a sitting position for some time] (65%), and d475 Driving [being in control] (55%). A large number of categories from the chapter 7: Interpersonal interactions and relationships were identified as well as work-related categories of the chapter 8: Major life areas.

Figure 4: Prevalence of impairment in the ICF categories of the component 'Activities and Participation'. Graphs present the proportional distribution of ICF qualifiers relevant to over 30% of the sample (cut-off for reporting)

*Extension categories to ICF Checklist based on linking of outcome measures in sleep medicine
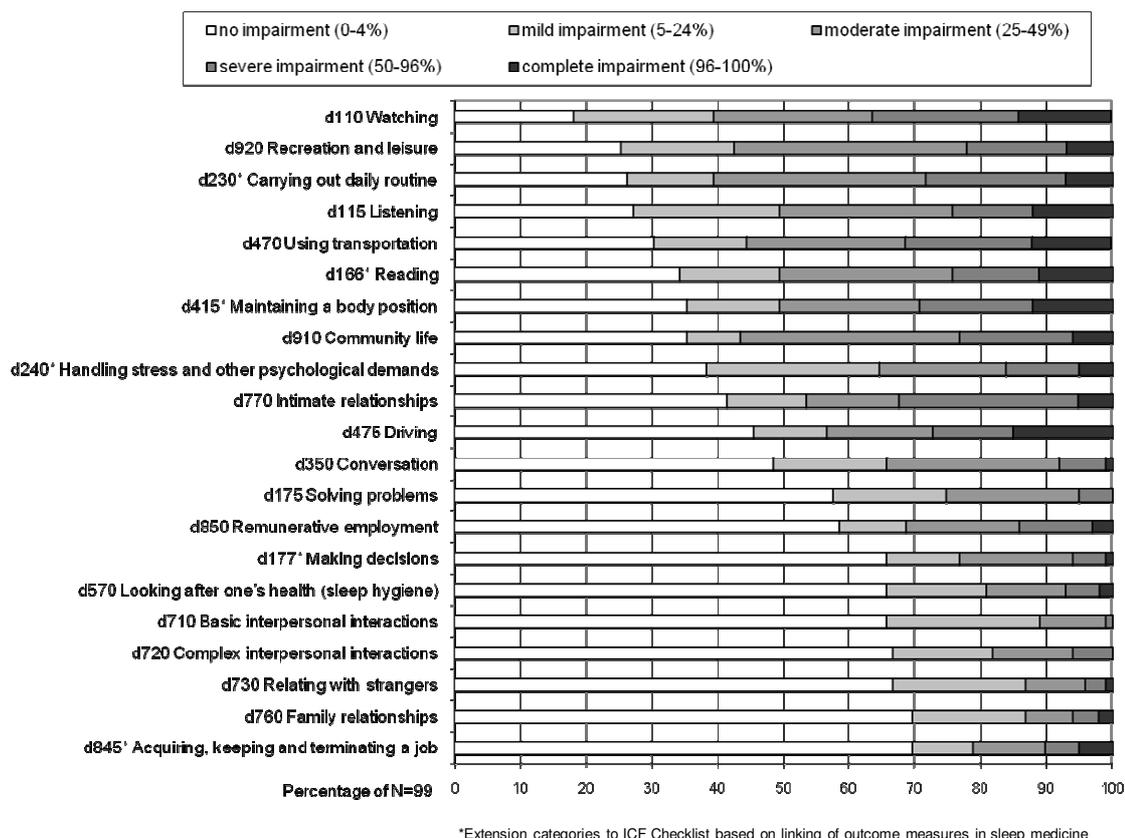
Environmental Factors

Within the component environmental factors the categories e310 Immediate family (79%), e110 Products or substances for personal consumption [i.e. medication] (62%), and e580 Health services, systems and policies (59%) were the most important facilitators; e245 Time-related changes [including circadian influences] (47%), e240 Light (41%), Climate (36%), and e250 Sound (36%) were the most important barriers in the natural environment. In chapter 3 Support and relationships and chapter 4: Attitudes a variety of relevant factors in the work and private life were identified. E355 Health professionals and e450 Individual attitudes, e330 People in positions of authority [i.e. supervisors at work] as well as e325 Colleagues appeared as important facilitators and barriers in the realm of formal relationships. Adapted devices like assistive breathing equipment was captured as both facilitator and barrier in the category e115 Products and technology for personal use in daily living.

Figure 5: Prevalence of facilitators (left) and barriers (right) in the ICF categories of the component 'Activities and Participation'. Graphs present the proportional distribution of ICF qualifiers relevant to at least 20% of the sample (cut-off for reporting)
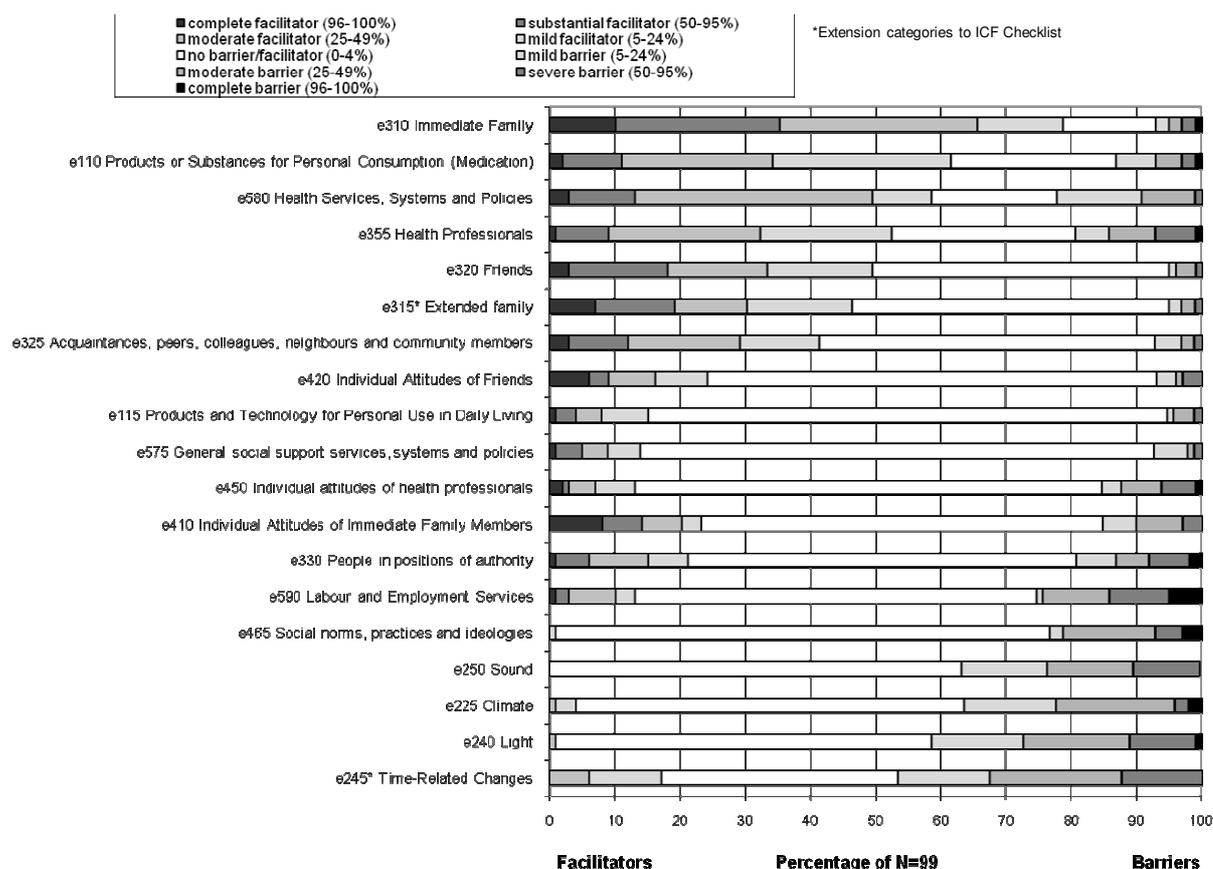
DISCUSSION

This is the first study that is comprehensively addressing the problems in functioning of persons with sleep disorders in a clinical setting. The results deliver a large variety of functional problems reflecting the complexity of the lived experience of persons with sleep disorders. This study also underlines the suitability of the ICF classification system in the description of sleep disorders through its offering a common denominator for the holistic, multi-disciplinary and multi-professional evaluation characteristic to sleep medicine (AASM, 2008, Pevernagie et al., 2009).

Regarding the functional outcomes of the Extended ICF Checklist, comparative and consistent findings related to the different sleep disorders are scarce. Our study is the first study that is exploring a clinical population of persons with any kind of primary sleep disorders and that is comprehensively assembling relevant variables of functioning as defined by the ICF.

With a sheer number of some 162 variables assessed it is impossible to report and give credit to all of them individually. The following discussion therefore remains on a

conceptual level and seeks to pick out some bio-psycho-social aspects of the lived experiences that we believe are crucial to the persons concerned as well as to sleep medicine in general.

Whereas most biomedical aspects which are captured in the ICF components of body functions and body structures should be intuitively apprehended by the inclined reader, it is with the component activities and participation and environmental factors where one might gain new insights.

A critical aspect of participation is reflected in our findings about interpersonal interactions and relationships. Bedpartners are usually the first observers and first aggrieved party -apart from the sleep-disordered patient- that note and recognize sleep problems. Marital relationships were accordingly researched in some quantitative studies and found to be a relevant issue (McFadyen et al., 2001, Kajaste et al., 2004), especially with regard to adherence to treatment with continuous positive airway pressure (CPAP) in Sleep-realted breathing disorders (SRBD) (Cartwright, 2008, Baron et al., 2009). Qualitative studies evaluating this important factor in the immediate environment of patients with sleep disorders are gradually evolving (Reishtein et al., 2006). Furthermore, social isolation as an outcome of sleep disorders should not be underestimated (Cacioppo and Hawkley, 2003, Rutenfranz et al., 1977). We are therefore inclined to support the notion of encouraging the sleep-disordered client to bring their bedpartners to consultations.

There are different studies that show that sleep disorders often affect the whole family situation at home (Meijer and van den Wittenboer, 2007, Brand et al., 2009). From paediatrics we further learn that including the whole family in comprehensive treatments increases family well-being and behaviour (Eckerberg, 2004). Successful therapy in SRBD- patients not only increases the patient's quality of life but also that of the bedpartner (Parish and Lyng, 2003). However, it is the first time that a study shows that the family environment can be experienced as a facilitator or a barrier in the life of persons with sleep disorders.

Aspects of relationships and environmental factors not only reach out significantly to the private life, but also to working life. Our finding about this major life area and colleagues and supervisors being important facilitators and barriers empathically pushes this claim. A recent study demonstrated that bullying at the workplace is associated with 4- to 5-fold increase in reported sleep disturbance (Niedhammer et al., 2009). We would therefore like to encourage any sleep medicine practitioner to

include the standard questions of 'How is it going at home/work?' into his everyday procedures.

Our findings about the importance of services, systems and policies in the component environmental factors is supported by research about issues like the difficulty of getting the proper diagnosis and treatment, the lack of awareness of available treatment options, or the persons' perception of available treatment options as ineffective or unattractive (Stinson et al., 2006, Flemons et al., 2004, Garrett et al., 2009, Phillips, 2007).

Controversially, the health professional appears to be both an important facilitator and barrier, reflecting the good and bad experiences patients make with their care providers. Congruently, a holistic (Morin, 2006, Meltzer et al., 2009) and effective treatment approach (Martin et al., 2004) and a sound and lasting doctor-patient relationship have been emphasized (Dikeos and Soldatos, 2005, Rosenthal, 2008, Collins et al., 2007).

The finding about the health system might also pertain to the lack of knowledge about sleep disorders in primary care (Hening et al., 2004, Ting and Malhotra, 2005, Namen et al., 2002), related under-diagnosis of sleep disorders (Kapur et al., 2002, Doghramji, 2004, Smith et al., 2002), and resulting negative and potentially stigmatising experiences that sleep disordered patients experience through misdiagnoses and uncertainty about their condition (Stores, 2007, Kryger et al., 2002). It has been stressed that clinical psychology training in sleep specialists of related disciplines is lacking (Meltzer et al., 2009). We conclude that an increased recognition of the patient's lived experience and psychosocial state might here counteract problems in the doctor-patient relationship.

Limitations

When interpreting these results some issues should be considered. First, the study represents the German-speaking Swiss perspective only. Especially within the component environmental factors and the not-yet classified component personal factors, cultural differences were not considered. Second, the sample size does not allow subgroup analyses and comparison among the different sleep diagnosis. By conducting a convenience sampling method, some patient groups (e.g. SRBD) are furthermore overrepresented and did accordingly have an impact on the overall outcome.

With regard to the Extended Checklist some comments might be indicated. First of all, there is no existing information about how the original ICF Checklist was developed. It is indeed questionable whether this is a valid questionnaire that can be applied generically to various health conditions at all (Ewert et al., 2004, Koskinen et al., 2007, Tenorio-Martinez et al., 2009). In order to answer to this problem, we extended the original ICF Checklist with additional categories that we identified through a systematic review and content analysis of most widely used measures in sleep medicine. The finding that some of the extension categories have scored highly overall (e.g. b126; d230; e315) is ample proof of concept for the need to extend the ICF Checklist in order to comprehensively capture the lived experience of persons with any kind of sleep disorders. Furthermore, the ICF Checklist collects data on the second level of specification regardless of what information is included in the subcategories of the classification system. This - along with the questionable reliability of the ICF qualifiers - represents a major challenge to a fair and valid evaluation of functioning domains (Okochi et al., 2005). We seek to counter this flaw by thoroughly educating the assessors about content and structure of the ICF and by having had a single assessor conducting all interviews.

It is important to stress that this is a first explorative study using an ICF based tool whose objective was to deliver a broad and varied cross-sectional snapshot from the clinical perspective. This will serve as an indicative evidence base among other studies conducted for the international consensus process in developing the ICF Core Sets for Sleep Disorders.

In no way do the results and discussion claim to be representative of general and larger populations of sleep disordered patients. The further validation of these results, larger cross-cultural studies and the development of an ICF based, functioning related sleep questionnaire are planned and will give more weight to these first, indicative results.

CONCLUSION

This study shows that sleep disorders are associated not only with a large number of impairments in body functions and body structures but also with activity limitations and participation restrictions, and that the environment can play an essential role in the life of persons with sleep disorders. These aspects of the lived experience of persons with sleep disorders should be systematically taken into account in the

assessment and treatment in sleep medicine. The ICF offers a unique, internationally accepted and comprehensive framework to systematically show that all these issues are relevant from the perspective of persons with sleep disorders. These results of ICF-based sleep research and the subsequent ICF Core Sets for Sleep Disorders are a first step into the direction of patient-centred and comprehensive assessments in sleep medicine.

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Problems in functioning from the patient perspective using the International Classification of Functioning, Disability and Health (ICF) as a reference

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Summary

We conducted a qualitative, multicenter study using a focus group design to explore the lived experiences of persons with any kind of primary sleep disorder with regard to functioning and contextual factors using six open-ended questions related to the ICF components. We classified the results using the International Classification of Functioning, Disability and Health (ICF) as a frame of reference.

We identified the meaningful concepts within the transcribed data and then linked it to ICF categories according to established linking rules. The six focus groups with 27 participants yielded a total of 6986 relevant concepts which were linked to a total of 168 different 2nd-level ICF categories. From the patient perspective, the ICF components (a) Body Functions, (b) Activities and Participation and (c) Environmental Factors were equally represented, while (d) Body Structures appeared poignantly less frequently. Out of the total number of concepts, 1843 concepts (26%) were assigned to the ICF component Personal Factors, which is not yet classified but could indicate important aspects of resource management and strategy development of those who have a sleep disorder. Therefore, treatment of patients with sleep disorders must not be limited to anatomical and (patho-) physiologic changes, but should also consider a more comprehensive view which includes patient's demands, strategies and resources in daily life and the contextual circumstances of the individual.

INTRODUCTION

Sleep Disorders, whether primary or secondary, are associated with a wide range of functional impairments that may be associated with activity limitations and participation restrictions (Verster et al., 2008). Sleep disorders have associated negative consequences on work performance (Daley et al., 2009, Sjosten et al., 2009, Sivertsen et al., 2009) and driving (Pandi-Perumal et al., 2006), which can lead to indirect public health costs. Therefore, a systematic and comprehensive understanding of the impact of sleep disorders on functioning is important to adequately recognize, optimally manage, and treat sleep disorders (Colten and Altevogt, 2006).

For the World Health Organization (WHO), functioning and the ability to participate in everyday life can be understood not only as a mere consequence of disease and its treatment, but also within the context of the person that may differ greatly depending on that person's private and societal background (WHO, 1993). This would imply that the biological, psychological, social and environmental aspects of everyday life must be taken into account to have a comprehensive perspective of health.

Qualitative methodology provides the possibility to explore the perspective of those who experience the disease (eg. patients) (Kvale, 1996). Compared to quantitative methodology, the qualitative approach promises a greater openness to unexplored concepts or phenomena (Patton, 1990) and focuses on how people understand and interpret their social worlds (Hayhow and Stewart, 2006). Qualitative methods are increasingly accepted in health research and health-related sciences (Giacomini and Cook, 2000, Mays and Pope, 2000).

Qualitative methods in sleep medicine have been applied in the nursing field (Hsu et al., 2009, Lee et al., 2007, Dickerson and Kennedy, 2006, Johansson et al., 2007, Crew, 2006), pediatrics (Tse and Hall, 2008, Kennedy et al., 2007) and social sciences (Henry et al., 2008). One study applied focus group methodology to explore the lived experience of insomnia and found evidence on the importance of relationships with significant others and health professionals (Carey et al., 2005). Considering the complexity and high burden associated with sleep disorders, qualitative research in the field of sleep medicine is generally scarce. Moreover, qualitative investigations around the variety of problems in functioning in persons with sleep disorders are lacking in the literature. .

The aim of this study is to determine relevant aspects of functioning as well as relevant contextual environmental and personal factors from the patient perspective using qualitative methodology.

METHODS

Design

We conducted a multicenter qualitative study using focus group interviews as part of a larger project on the development of ICF Core Sets for sleep disorders. This study was one of the four preparatory studies of the project to gather information about the relevance of functional problems in people with sleep disorders (Stucki et al., 2008). The study was approved by the responsible Ethics Committee for each the study centres and was performed in accordance with the Declaration of Helsinki.

Participants

Patients from three sleep centers were recruited by convenience sample.. In order to obtain a comprehensive picture of the whole continuum of clinical care (i.e. maximum variation (Patton, 1990)), patients of any etiopathology (first contact, control after first contact/polysomnography, under treatment, and chronic) were included. Maximum variation in the sample means that we aim to explore the broadest and diversified range of possible accounts of living with different sleep disorders, rather than making a comparative account of different diagnostic groups.

Individuals were included in the study if they (1) had a diagnosis of a primary sleep disorder according to the 2nd edition of the International Classification of Sleep Disorders, (2) were older than 18 years of age, (3) spoke the German language, (4) had been attested to be sane (compos mentis) and capable of making decisions by the discretion of the investigator or health professional, (5) had been informed of the purpose and rationale of the study, and both had been understood, and (6) had signed the patient consent form. Individuals with significant cognitive impairment or whose main diagnosis is a major psychiatric or psychological disorder were excluded. Given that an ICF Core Set for depression has also been developed (Cieza et al., 2004), we ensured that all participants included in the study had a sleep disorder as the primary problem.

Sample Size

The sample size was determined by calculating the saturation (Patton, 1990). Saturation refers to the point during data gathering when the linking of the qualitative data of two consecutive focus groups revealed no more than five additional new concepts compared to previous focus groups (Krueger and Casey, 2000, Depoy, 1998).

Materials

The International Classification of Functioning, Disability and Health (ICF) adopted by the World Health Organization in 2001 (WHO, 2001) was used as a reference to analyse the data. The overall aim of the ICF classification is two-fold: to offer a common framework for all health professions based on the bio-psycho-social perspective and to provide a unified and standard language for the description of health and health-related domains (WHO, 2001).

The ICF classification, distinguishes functioning into 5 components namely (1) Body Functions and (2) Body Structures, (3) Activities and Participation, (4) Environmental Factors, and (5) Personal Factors. Each component consists of several chapters, with hierarchical ICF categories as the units of classification (WHO, 2001). The ICF components make up more than 1,400 ICF categories, with the exception of Personal Factors, which has not yet been classified. Each ICF category is assigned an alphanumeric code- a letter that refers to the components of the classification (b: Body Functions; s: Body Structures; d: Activities and Participation and e: Environmental Factors) and is followed by a number or numbers starting with the chapter number (one digit) and followed by the second-level specification (three digits), and when applicable, further third- and fourth-level specification..

An established topic guide was previously used and developed by our group (Stamm, 2007, Kirchberger, 2009). This guide describes how to prepare and perform focus group sessions using the open-ended questions. The following open-ended questions based on the ICF components were used:

(1) If you think about your body and mind, what does not work the way it is supposed to? [Body Functions]

(2) If you think about your body, in which parts are your problems? [Body Structures]

(3) If you think about your daily life, what are your problems? [Activities & Participation]

(4) If you think about your environment and your living conditions, what do you find helpful or supportive? [Environmental Factors - facilitators]

(5) If you think about your environment and your living conditions, what barriers do you experience? [Environmental Factors - barriers]

(6) If you think about yourself, what is important about you and the way you handle your disease? [Personal Factors]

Data collection

Focus group interviews were conducted in a nondirective manner by the same moderator (BK) who is experienced in working with the ICF and in conducting patient interviews. The moderator has not been involved in any medical treatment of the focus group participants prior to the study. All focus group interviews were conducted according to standardized guidelines to include open-ended questions and instructions such as introduction, procedure of the session, and other technical aspects.

Data analysis

Qualitative analysis

The meaning condensation procedure (Kvale, 1996) was used as the basis of the qualitative analysis of data. In the first step, the transcripts of the focus groups were screened to get an overview of the collected data. In the second step, the data were divided into 'meaning units' and the theme that dominated a meaning unit was determined. A meaning unit was defined as a specific unit of text with either a few words or a few sentences with a common theme (Karlsson, 1995). A meaning unit division does not follow linguistic grammatical rules. The text was divided where the researcher discerned a shift in meaning (Kvale, 1996). Finally, the concepts contained in the meaning units were identified. A meaning unit could contain more than one concept.

Linking to the ICF

The identified concepts were linked to the categories of the ICF based on established linking rules (Cieza et al., 2002, Cieza et al., 2005), which allow concepts to be linked

to the ICF categories in a systematic and standardized way. There were some important concepts which cannot be classified within the ICF, namely Personal factors ('PF'), health condition ('Hc'), concepts that relate to the ICF but cannot be assigned a particular component or code ('Nd'), and concepts outside of the ICF framework ('Nc').

In order to avoid possible bias (improve reliability) between two linkers, calibration linking was performed by two different health professions who are trained in the ICF linking. We calculated the frequency of linked categories for the different focus groups and the overall frequency that each category has been identified.

Quality of Data

Several strategies were used to improve and verify the trustworthiness of the qualitative data. First, data triangulation was applied to ensure the comprehensiveness of data by using two data analysts (investigator triangulation, multiple coding) (Denzin, 1978, Barbour, 2001). Second, continuous data analysis was used according to Pope et al. (Pope and Mays, 2000). Third, reflexivity was assured by conducting a research diary for the documentation of memos concerning the design, data collection and analysis of the study. Fourth, clear exposition was used establishing guidelines for conducting the focus groups (including open-ended questions), verbatim transcription, and implementing the linking rules (Cieza et al., 2002, Cieza et al., 2005). By using these strategies, we are confident that an appropriate account of the methods of data collection and analysis was assured.

RESULTS

Description of the focus groups

A total of 27 patients participated in 6 focus groups with a mean age of 48.96 yrs. Majority of the participants were female (59.3 %). Of the 27 patients, diagnoses of a primary sleep disorder specifically included four insomnia, ten sleep-related breathing disorders, nine hypersomnias of central origin, two sleep-related movement disorders, and two with multiple sleep diagnosis.

The progress of saturation is displayed in Figure 1:

Saturation of the qualitative data
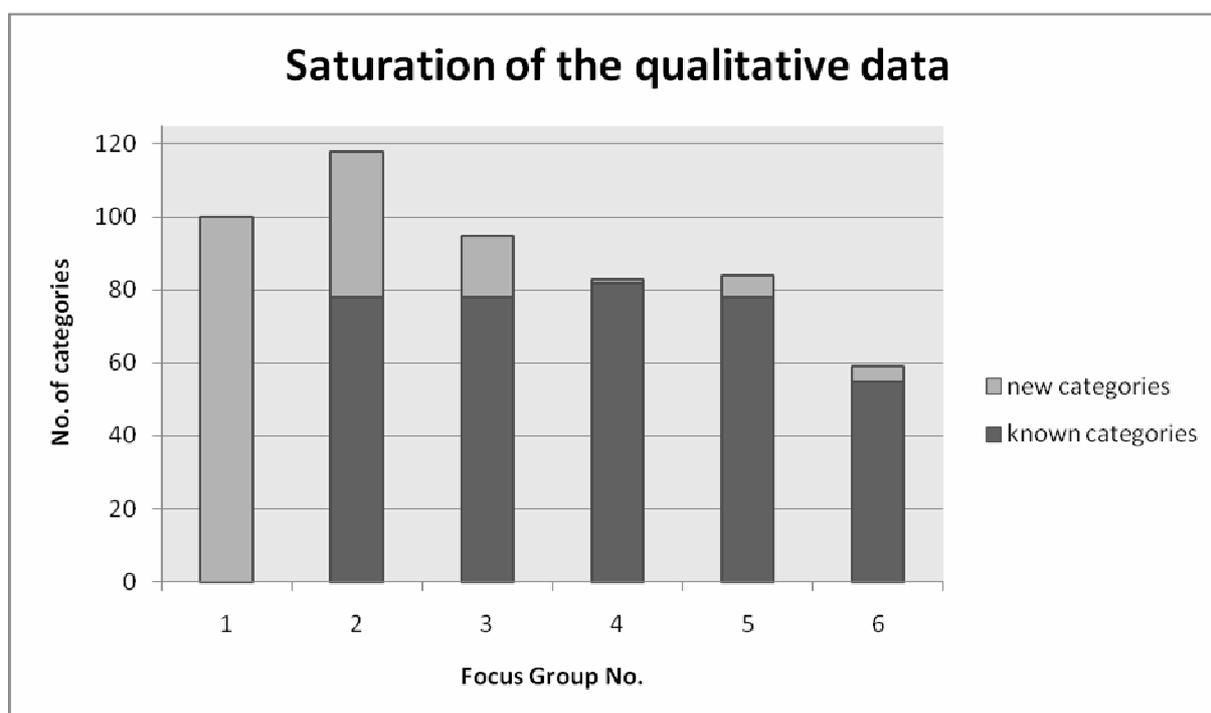
Qualitative analysis and linking

A total of 6986 relevant ICF linkings were performed in the focus groups and linked to 168 different 2nd-level categories. Out of these 168 categories, we identified 53 (31.5%) categories belonging to Body Functions, 57 (33.9%) categories belonging to Activities and Participation, and 48 (28.6%) categories belonging to Environmental Factors. Ten (6%) categories belonged to Body Structures. For those concepts that were not classified but linked, 1844 (26.4%) belonged to the ICF component Personal Factors, 323 (4,6%) were coded as 'Nd', 157 (2.2%) as 'Hc', and 71 (1%) were 'Nc'.

Body Functions

Table 1 shows the 2nd level categories identified for the component Body Functions. The top five categories most frequently mentioned in each focus group are b134 Sleep functions (486 linkings), b130 Energy and drive functions (375 linkings), b126 Temperament and personality functions (175 linkings), b140 Attention functions (46 linkings), and b455 Exercise and tolerance functions (38 linkings). Below is a quote illustrating some of these categories by an individual with narcolepsy (related concepts in italics and linking examples in brackets):

"…the *tiredness* [b1300 Energy level], and sometimes *the capacity to concentrate* [b140 Attention functions]. Especially when I have one of these *sleep*

attacks [b134 Sleep functions], I am definitely *more irritable* [b1263 Psychic stability]…"

Table 1:   53 2nd level categories of component *Body Functions* (b): Number of focus groups in which ICF categories (2nd-level) were mentioned by the participants. Number of linkings across all focus groups.

Body Functions		N	N 2)
b110	Consciousness functions	5	86
b114	Orientation functions	4	6
b122	Intellectual functions	1	3
b126	Temperament and personality functions	6	175
b130	Energy and drive functions	6	375
b134	Sleep functions	6	486
b140	Attention functions	6	46
b144	Memory functions	4	21
b147	Psychomotor functions	4	14
b152	Emotional functions	5	93
b156	Perceptual functions	5	19
b160	Thought functions	5	30
b164	Higher-level cognitive functions	4	40
b167	Mental functions of language	2	3
b180	Experience of self and time functions	5	35
b210	Seeing functions	4	20
b215	Functions of structures adjoining the eyes	5	15
b220	Sensations associated with the eye and adjoiningstructures	3	6
b230	Hearing functions	4	10
b240	Sensations associated with hearing and vestibularfunctions	2	11
b250	Taste functions	1	1
b260	Proprioceptive functions	1	2
b265	Touch functions	3	3
b270	Sensory functions related to temperature and otherstimuli	3	7
b280	Sensations of pain	5	63
b330	Fluency and rhythm of speech	1	4
b410	Heart functions	3	7

b415	Blood vessel functions	1	2
b420	Blood pressure functions	1	4
b430	Haematological system functions	1	2
b435	Immunological system function	1	1
b440	Respiration functions	3	21
b445	Respiratory muscle functions	1	1
b450	Additional respiratory functions	5	16
b455	Exercise tolerance functions	6	38
b460	Sensations associated with cardiovascular and respiratory functions	2	6
b515	Digestive functions	1	1
b530	Weight maintenance functions	5	30
b535	Sensations associated with the digestive system	1	5
b620	Urination functions	1	1
b640	Sexual functions	1	1
b710	Mobility of joint functions	2	2
b715	Stability of joint functions	1	1
b730	Muscle power functions	5	6
b735	Muscle tone functions	4	79
b755	Involuntary movement reaction functions	1	1
b760	Control of voluntary movement functions	4	8
b765	Involuntary movement functions	3	5
b770	Gait pattern functions	1	1
b780	Sensations related to muscles and movement functions	3	8
b830	Other functions of the skin	3	7
b840	Sensations related to skin	1	1
b850	Functions of hair	2	2

[1] Number of focus groups (N=6) mentioning the respective ICF category

[2] Number of linkings across all focus groups (N=6).

Body Structures

Table 2 shows the 2nd level categories identified for the component Body Structures. The ICF category s750 Structure of lower extremity (mentioned in 4 focus groups, 14 linkings) and s710 Structure of head and neck region (mentioned in 3 groups, 3 linkings) were considered.

Table 2:   Ten 2nd level categories of component *Body Structures* (s): Number of focus groups in which ICF categories (2nd-level) were mentioned by the participants. Number of linkings across all focus groups.

Body Structures		N [1]	N [2]
s110	Structure of brain	1	2
s220	Structure of eyeball	1	1
s310	Structure of nose	2	2
s320	Structure of mouth	1	2
s710	Structure of head and neck region	3	3
s730	Structure of upper extremity	2	8
s750	Structure of lower extremity	4	14
s760	Structure of trunk	1	11
s770	Additional musculoskeletal structures related to movement	1	3

[1] Number of focus groups (N=6) mentioning the respective ICF category

[2] Number of linkings across all focus groups (N=6).

Activities & Participation

Table 3 shows the 2nd level categories identified for the component Activities and Participation.

The top five categories identified and mentioned in each of the focus groups are d850 Remunerative employment (212 linkings), d920 Recreation and leisure (190 linkings), d230 Carrying out daily routine (106 linkings), d415 Maintaining body position (50 linkings), and d240 Handling stress and other psychological demands (50 linkings).

Table 3:   57 2nd level categories of component *Activities & Participation*
(d): Number of focus groups in which ICF categories (2nd-level) were
mentioned by the participants. Number of linkings across all focus groups.

Activities & Participation		N [1]	N [2]
d110	Watching	4	17
d115	Listening	1	2
d155	Acquiring skills	2	2
d160	Focusing attention	3	3
d166	Reading	5	24
d175	Solving problems	1	2
d177	Making decisions	1	4
d210	Undertaking a single task	1	1
d220	Undertaking multiple tasks	3	5
d230	Carrying out daily routine	6	106
d240	Handling stress and other psychological demands	6	50
d310	Communicating with - receiving – spoken messages	3	6
d315	Communicating with – receiving – nonverbal messages	1	2
d330	Speaking	5	7
d335	Producing nonverbal messages	2	4
d345	Writing messages	1	2
d350	Conversation	5	11
d355	Discussion	3	5
d360	Unsing communication devices and techniques	5	6
d410	Changing basic body position	1	2
d415	Maintaining a body position	6	50
d430	Lifting and carrying objects	1	1
d435	Moving objects with lower extremities	1	2
d450	Walking	3	6
d455	Moving around	2	6
d460	Moving around in different locations	2	2
d465	Moving around using equipment	1	3
d470	Using transportation	4	28
d475	Driving	6	45
d520	Caring for body parts	1	2

d540	Dressing	2	3
d550	Eating	5	21
d560	Drinking	1	1
d570	Looking after one's health	5	40
d620	Acquisition of goods and services	4	15
d630	Preparing meals	6	14
d640	Doing housework	6	43
d650	Caring for household objects	3	14
d660	Assisting others	6	19
d710	Basic interpersonal interactions	5	22
d720	Complex personal interactions	4	15
d730	Relating with strangers	5	7
d740	Formal relationships	4	6
d750	Informal social relationships	4	12
d760	Family relationships	5	34
d770	Intimate relationships	6	30
d820	School education	3	7
d840	Apprenticeship (work preparation)	2	10
d845	Acquiring, keeping and terminating a job	6	33
d850	Remunerative employment	6	212
d855	Non-renumerative employment	6	26
d865	Complex economic transactions	2	5
d870	Economic self-sufficiency	3	11
d910	Community life	6	24
d920	Recreation and leisure	6	190
d930	Religion and spirituality	2	4
d940	Human rights	6	31

[1] Number of focus groups (N=6) mentioning the respective ICF category

[2] Number of linkings across all focus groups (N=6).

Typical quotes from the focus groups are exemplified by the following patient with a severe chronic insomnia that he reported to have over the past 15 years and which severely impaired his ability to work:

"…I *don't work 100%* any more [d850 Remunerative employment], that is just not possible any more."

A person with sleep apnea elaborates on work as follows:

"the *work,* [d850 Remunerative employment] I still take that so seriously as to say: there you just have to, *you have to function* [Pf], with *the other things* [nd] you don't have to necessarily"

Or in interrelation with d240 Handling stress and other psychological demands by a person with narcolepsy:

„But it might happen, that I have *crisis* [b134 Sleep functions] *during work* [d850 Remunerative employment], and *this does stress me out* [d2401 Handling stress]"

Another quote by another patient with a serious case of insomnia in our sample:

"…I then pay for it *in the evening* [nc] in *leisure time with friends* [d9205 Socializing], then, I am not really any more, uh, always *prepared to be receptive* [b126 Temperament and personality functions]."

With regard to d415 Maintaining a body position the following patient with Restless Legs Syndrome (RLS) describes it as follows:

"I once *fell from a chair* [d4153 Maintaining a sitting position] because *I fell asleep* [b134 Sleep functions]"

A newly-diagnosed patient with sleep apnea summed it up for the group:

"But I believe the bottom line is: *we all suffer in everyday life* [d230 Carrying out daily routine]"

Environmental Factors

Table 4 shows the 2nd level categories identified for the component Environmental Factors.

The categories occurring most frequently and in each focus group are e310 Immediate family (168 linkings), e110 Products or substances for personal consumption (149 linkings), e410 Individual attitudes of immediate family (96 linkings), e580 Health services, systems and policies (85 linkings), and e355 Health professionals (84 linkings).

Table 4:   48 2nd level categories of component *Environmental Factors* (e): Number of focus groups in which ICF categories (2nd-level) were mentioned by the participants. Number of linkings across all focus groups.

Environmental Factors		N	N [2)]
e110	Products or substances for personal consumption	6	149
e115	Products and technology for personal use in daily living	5	47
e120	Products and technology for personal indoor and outdoor mobility	2	4
e125	Products and technology for communication	2	4
e135	Products and technology for employment	1	1
e150	Design, construction and building products and technology for public use	2	2
e155	Design, construction and building products and technology for private use	3	6
e160	Products and technology of land development	3	5
e165	Assets	1	3
e210	Physical geography	1	18
e225	Climate	5	27
e240	Light	3	21
e245	Time-related changes	4	25
e250	Sound	5	15
e260	Air quality	1	1
e310	Immediate family	6	168
e315	Extended family	2	5
e320	Friends	4	19
e325	Acquaintances, peers colleagues, neighbours and community members	6	79
e330	People in positions of authority	6	17
e340	Personal care providers and personal assistants	1	2
e345	Strangers	1	4
e350	Domesticated animals	3	7
e355	Health professionals	6	84
e360	Health-related professions	4	10
e410	Individual attitudes of immediate family members	6	96
e420	Individual attitudes of friends	3	16
e425	Individual attitudes of acquaintances, peers colleagues, neighbours	6	63
e430	Individual attitudes of people in positions of authority	3	16
e445	Individual attitudes of strangers	2	3
e450	Individual attitudes of health professionals	4	40
e455	Individual attitudes of health-related professionals	4	14
e460	Societal attitudes	4	32

e465	Social norms, practices and ideologies	5	22
e520	Open space planning services, systems and policies	2	4
e530	Utilities services, systems and policies	1	2
e535	Communication services, systems and policies	3	4
e540	Transporation services, systems and policies	4	7
e545	Civil protection services, systems and policies	1	2
e550	Legal services, systems and policies	1	1
e560	Media services, systems and policies	2	4
e565	Economic services, systems and policies	3	4
e570	Social security services, systems and policies	3	19
e575	General social support services, systems and policies	1	1
e580	Health services, systems and policies	6	85
e585	Education and training services, systems and policies	2	4
e590	Labour and employment services, systems and policies	4	13
e595	Political services, systems and policies	1	1

[1] Number of focus groups (N=6) mentioning the respective ICF category

[2] Number of linkings across all focus groups (N=6).

For example, one person with insomnia put it in this way, when stressing the impact of his sleep disorder on his social environment:

"…everything is afflicted by that: *the kids* [e310 Immediate family], *the wife* [e310 Immediate family], *the colleagues* [e325 Acquaintances, peers, colleagues, neighbours and community members]…"

A woman with idiopathic hypersomnia quoted the support she receives from her husband as follows:

"…I just *attend the family until 17:30h* [d760 Family relationships] and then my *husband comes in and takes over that part* [e310 Immediate family]"

Environmental factors may be facilitators, but they may also be perceived to be barriers as expressed in the following quote by a male patient with sleep apnea:

"…and I also have *a very understanding wife* [e410 Individual attitudes of immediate family members - Facilitator], and therefore…; *the first wife got a divorce* [d7701 Spousal relationships]…firstly because of the *snoring* [b450 Additional respiratory functions], and secondly because *she didn't have the nerves* [e410 Individual attitudes of immediate family members - Barrier]."

The 2nd level category e110 Products or substances for personal consumption comprises both e1100 Food and e1101 Drugs as sub-categories on the third level.

One example was mentioned by a woman living with insomnia:

"…for the past half year *I am eating chocolate* [e1100 Food], and I have the feeling that I am *getting myself the energy* [b130 Energy functions] through *food* [e1100 Food - facilitator]."

More frequently, however, medications were an issue, perceived to be both a facilitator and barrier. One person with narcolepsy elaborated:

"I don't take any *medication* [Pf], and I don't want to as long as possible, because they *don't do me any good* [e1101 Drugs - barrier]"

A patient with severe RLS stated:

"…at night, that would be unthinkable *without the two pills* [e1101 Drugs - facilitator], unthinkable!"

What concerns the categories representing the health system, many patients described their negative experiences they had to describe their health condition:

„…I went to see many *doctors* [e355 Health Professionals], who just didn't know it."

„…they sent me to the psychiatrist and *the psychiatrist, fortunately, he asked me after an hour, what I wanted* [e450 Attitudes of health professionals]"

"…when I went to *the sleep clinic* [e580 Health services] for the first time […], *he wanted to put it out like I was simulating* [e450 Attitudes of health professionals]"

Personal Factors:

A large part of the meaningful data identified was coded to belong to the component Personal Factors.

We were able to broadly distinguish between Personal Factors as person characteristics that remain unchanged during the trajectory of a health condition, and those strategies that persons with sleep disorders develop especially to cope with their disorder. These could be strategies that patients developed as they undergo with their treatment regimen. This theme was expressed in the following quote by a participant with narcolepsy:

„I strongly *differentiate between free time and work* [Pf], because I currently use [*medication*] [e1101 Drugs] for *work* [d850 Remunerative employment] only."

Relating to the aspect of visibility of sleep disorders and ensuing problems in social interactions, several strategies were mentioned:

"In former times, *I kept it under my hat* [Pf], right? Then, I did not, *did not say that I had something* [Pf].[…] today *I simply say it* [Pf], and then most likely *get up to move* [Pf] and say *I have problems with the legs* [b7650 Involuntary contractions of muscles]" [RLS patient]

"Like, sometimes *you somehow put on a mask* [Pf], so that *you can actually get through life* [nd]" [Sleep apnea patient]

„…*I did not have my coming-out yet* [Pf], I just said *I must sleep* [b134 Sleep function]. *No one in the office* [e325 Colleagues] knows that I have this problem. *I am very open, I say: I am doing my power-napping - please do not disturb* [Pf]. *Some of them even approve of this* [e425 Individual Attitudes of Colleagues]" [narcolepsy patient]

Generally, a major strategy and resource was 'taking time', developing positive sleep hygiene, and also balancing, controlling and planning daily activities.

"I always beg for time!" [person with insomnia]

"every afternoon I sleep in the office, in my office chair - else I cannot manage" [person with narcolepsy]

"I always try and sleep on my side" [Sleep apnea patient]

"I work with to-do-lists […] If I have the liberty to do what I want, and can schedule my day accordingly, then I am doing relatively well." [person with insomnia]

„…so that post-it's have become my best friends, I have simply just written down everything and somehow stuffed it in my pockets" [Sleep apnea patient]

DISCUSSION

Based on the accounts of the lived experiences of persons with sleep disorders, the patients face severe activity limitations and participation restrictions, combined with impaired body functions especially around role expectations in work and private life,. The interaction of the patient with contextual factors like family, work environment, individual and societal attitudes and the health system may act as barriers and facilitators.

Our qualitative data give evidence for the process of adaptation to a sleep disorder. This process is dominated by the experience of uncertainty before or during the time of diagnosis. This is accompanied by issues of legitimating and explaining deviant behaviour, unmet role expectations and falsely attributed symptoms and leads to a process of reorientation after diagnosis. This process of reorientation is expressed in a transfer to tight sleep hygiene regimens, strict time management, and self-control of daily activities. Our data suggests that persons affected by sleep disorders develop strategies (e.g. medication use, disclosure/concealment of diagnosis) and mobilize resources (e.g. family) in order to cope with the processes of adaptation.

When asked about their problems, patients rarely mention anatomical changes as represented by the ICF component Body Structures. However, (patho-) physiological changes, as represented by the ICF component Body Functions, as well as daily activities and participation in life, as represented by the ICF component Activities and Participation, and Environmental Factors are reported by the patients as being important.

A huge spectrum of Body Functions was mentioned by the participants of the focus groups, covering all of the chapters of this component. The most frequently identified categories in the component Body Functions mostly belonged to the component's first chapter: Mental functions. These categories pertain to well-known impairments and symptoms of many sleep disorders, like cognitive functions (Walker, 2009, Rakel, 2009, Panossian and Avidan, 2009, Ohayon, 2009), mood (El-Ad and Lavie, 2005, Ford and Cooper-Patrick, 2001, Haba-Rubio, 2005, Hasler et al., 2005, Sateia, 2009) and sleepiness, tiredness or fatigue (Roehrs et al., 2000, Briones et al., 1996, Chervin, 2000, Aguillard et al., 1998, Hossain et al., 2005, Lichstein et al., 1997, Mathis and Hess, 2009, Reimer and Flemons, 2003, Schneider et al., 2004, Valko et al., 2008).

Aspects of the component Activities & Participation were also reported to be important factors in living with sleep disorders, affecting all life areas including mobility, self-care (e.g. sleep hygiene), domestic life, and relationships. Predominantly, concepts linked around activities and participation were related to daily routine, work and private life, at time showing trade-offs between these major life areas (Basner et al., 2007). Research partly supports this finding in showing that combined with impairments on the level of body functions, work performance is limited (Eriksen et al., 2001, Bultmann et al., 2005, Leger et al., 2006, Sivertsen et

al., 2009, Sjosten et al., 2009, Rakel, 2009, Omachi et al., 2009, Daley et al., 2009, Bolge et al., 2009, Barger et al., 2009). Altogether, there are no other comparative and comprehensive studies that account for the sum of factors we identified through our study.

Similarly, the interaction of the person and his or her environment remains scarcely researched. The relevant environmental factors we identified cover all chapters of this ICF component which range from treatment interventions like medication and assisted ventilation, circadian elements represented by the natural environment, to aspects of the work environment. In our sample, patients mostly related to categories of chapter 3 Support and relationships of the ICF component on environmental factors and also their engagement with health services and health professionals.

Emerging research supports the importance of including the patient perspective through comprehensive and multidisciplinary designs. Especially in paediatrics, models have been developed that seek to understand the interdependence of sleep, behaviour, the family and the physical and social environment (Beebe, 2008, Brand et al., 2009). The critical importance of social support and possible conflicts arising from families seeking to cope with disability have been stressed (Ell, 1996).

Explorations into behavioural correlates with adherence to continuous positive airway pressure treatment in patients with sleep-related breathing disorders further stress the importance of including the patient perspective holistically (Broström et al., 2010). Whereas it seems that personal factors like self-efficacy before contact with the health system do not predict Continuous Positive Airway Pressure (CPAP) post-treatment, the patient perception in the first week of treatment accounts for approx. 20-30% of the variance in CPAP use (Wild et al., 2004, Weaver, 2005). The narratives of our patients stress the importance of the initial clinical encounter, and how the interaction with health professionals is critical for them. The reports of negative experiences with health care providers that are not trained in treating and diagnosing sleep disorders (Papp et al., 2002), or wrongly diagnosing these patients, and suggesting different treatment options (Buysse et al., 1997, Kapur et al., 2002, Chokroverty, 2003) are evident based on our study. The importance of education, caregiver relationship and social networks, however, remain underestimated (Aloia, 2009, Vourlekis and Ell, 2007, Ell, 1996, Brostrom et al., 2009, Collins et al., 2007). Our study adds further evidence to support the interrelation and importance of the factors mentioned earlier.

About a quarter of our ICF-linkings were coded as personal factors. This stresses the importance of the individual or personal context variation in living with sleep disorders that also include important aspects of psychosocial factors, resource management and strategy development. Unfortunately, Personal Factors cannot be coded like the other components in the ICF model. ICF broadly suggest that Personal Factors may comprise factors like gender, race, age, lifestyle, habits, coping styles, education, past and current experiences, behavior patterns, character style, and psychological assets ((WHO, 2001)p. 17). However, the authors of the ICF and other institutions like the Institutes of Medicine (IOM, 2007, Whiteneck, 2006) have stressed the importance of personal factors and have suggested to structure and classify them (Heerkens et al., 2004, Stephens and Kerr, 2000, Viol et al., 2006, Viol et al., 2007, Ueda and Okawa, 2003).

Nevertheless, some interesting findings on Personal Factors could be detected. One of many of such examples for Personal Factors is the problem of the visibility of the disability experience associated with sleep disorders. In this context, subtle differences in self-perceptions between the diagnostic groups could be detected, e.g. the insights related to legitimizing and justifying the disorder offered by this obese person with sleep apnea as she responded to a person diagnosed with narcolepsy:

    "There are decent and indecent diseases, you [addressing the person with narcolepsy] have a decent one. If I wasn't overweight, I could point out clearly that I am not responsible…"

Relating to the diagnostic group of narcolepsy, which were predominantly represented in our sample, further insights into their coping style and behavior patterns could be detected. Given the degrees of uncertainty after onset of symptoms (Lorence and Hummel, 2006), before and after diagnosis (Broughton and Broughton, 1994, Wilson et al., 2007) and the chronic nature of narcolepsy, this patient group seems to be overtly challenged to develop distinct strategies of coping with a disorder that is not directly visible in the interaction with the environment, but more evident through performance-related problems than other sleep disorders (Schneider et al., 2004, Teixeira et al., 2004, Bayon et al., 2009). Analogous to findings in epilepsy (Faircloth, 1999, Schneider and Conrad, 1981), we were able to distinguish typological behavior in social encounters and in disclosing or hiding the disorder, ranging from a secretive, to a pragmatic type selectively concealing their disorder, to a quasi-liberated type that naturally confronts others with their health condition.

Our study has several limitations. From these findings it cannot be concluded that the encountered functional problems are equally relevant and representative for all sleep disorders or all people living with a specific sleep disorders. The rather less clinically prevalent sleep disorders, like for example, parasomnias and circadian rhythm sleep disorders, are not represented in our sample. The predominance of diagnoses of narcolepsy and sleep related breathing disorders in our sample may have further biased our finding towards functional problems related to the leading symptoms of hypersomnia or sleepiness within these groups. Neither is this study taking into account cultural variation (Bliwise, 2008), using a German-speaking participants in Switzerland. Sleep disorders often develop in early years of age and by excluding persons below the age of 18, specific aspects of age-related issues could only be detected through retrospective reflections and narratives of our participants. These must be considered major limitations, and further qualitative studies with different diagnostic groups in different parts of the world would be desirable.

The number of focus groups in which a specific problem was mentioned and the frequency with which this problem was accounted, may provide an impression about the relevance of a problem. In addition, one might argue that the questions in the topic guide are leading in nature and that several participants of one and the same diagnosis might have dominated the topics discussed in one focus group. However, as documented in the research diary, participants tended to freely diverge from the direction given in the open-ended questions. They appeared to follow a hierarchy of degrees of current or recollected suffering, and this degree of freedom stimulated the interaction between all participants. Above all, it is essential to take into account that the qualitative methodology used in this study which was aimed at identifying the broadest possible range of problems. This was also done in order to provide - along with another patient study using semi-structured interviews and a larger sample - a decision base for the consensus process in the development of ICF Core Sets for Sleep Disorders (Stucki et al., 2008). The determination of the prevalence of problems for the separate sleep disorders or different etiopathologies needs further investigation using mixed methods and comprehensive designs.

Conclusion:

The study provides evidence on the importance of comprehensive conceptualisations applying qualitative methodology and helps to holistically understand and address the impact of sleep disorders based on the bio-psycho-social model of the ICF.

Following the principle 'nothing about us without us'(UN, 2006), the data we gathered directly from the patient perspective would serve as a basis to develop and adopt international standards for comprehensively describing the functioning in individuals with sleep disorders.

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Supplementary information to be posted on the journal's web site

Figure 1: **The current framework of functioning and disability – the WHO International Classification of Functioning Disability and Health (ICF)**
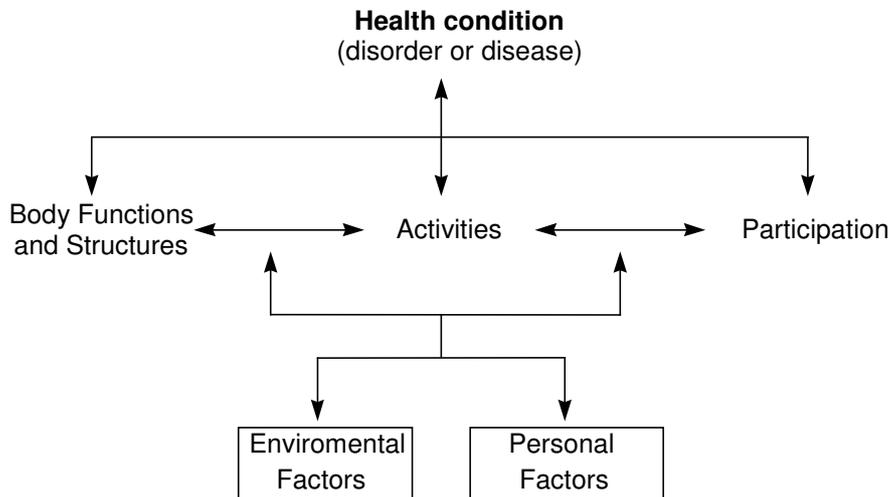

Figure 2: **Structure of the ICF classification**

Hierarchical structure of the ICF (WHO, 2001; the figure has been reprinted with permission of the WHO, all rights are reserved by the Organization)
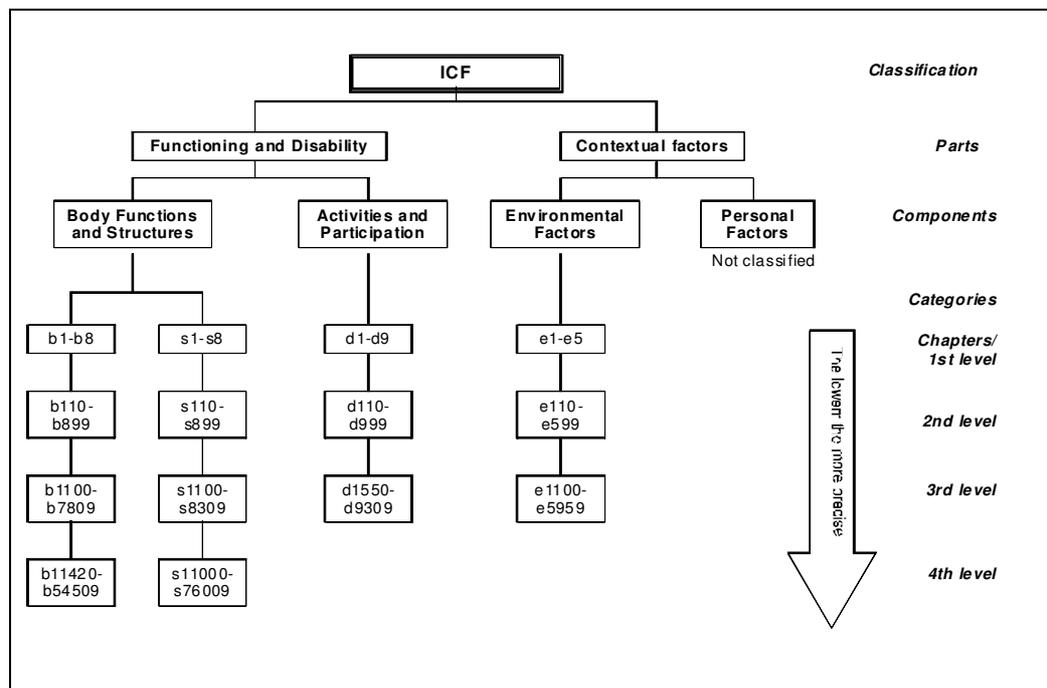
Identification of problems in functioning of persons with sleep disorders from the health professional perspective using the International Classification of Functioning, Disability and Health (ICF) as a reference: a worldwide expert survey

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Short title:

Expert perspective on functioning in Sleep Disorders

Keywords

Sleep Disorders; Expert Survey; ICF; ICF Core Set, Functioning

Abstract

Objectives

The objective of this study is to identify relevant aspects of functioning as well as related environmental factors from the perspective of health professionals worldwide experienced in treating persons with any kind of (primary) sleep disorder.

Methods

A structured email survey was sent to 174 selected international experts. Using 6 open-ended questions physicians, nurses, therapists, technicians, biologists and psychologists were asked to indicate the problems in functioning experienced by individuals with (primary) sleep disorders including the contextual factors like environmental and personal factors which influence functioning. The International Classification of Functioning, Disability and Health (ICF) was used as a frame of reference to analyse the data. All answers were translated ('linked') to the ICF based on established coding rules. Absolute and relative frequencies of the linked ICF categories were reported.

Results

One hundred and twenty-three experts (70.7 %) from 6 World Health Organization (WHO) regions (54 countries) mentioned 5.200 themes which were linked to 7256 ICF categories. The majority of these linkings (33.3%) were attributed to 58 different ICF categories of the ICF component body functions, followed by 21.8% of linkings to 52 categories of environmental factors, 16.1% of linkings to 49 different categories in activities & participation, and 9.7% of linkings to 29 categories of body structures.

Conclusion

Health professionals addressed a large variety of functional problems reflecting the complexity of sleep disorders. The ICF provided a comprehensive framework in order to integrate answers from different professional backgrounds and different world regions.

INTRODUCTION

The delivery of care in sleep medicine requires the clinical encounter with medical specialists of various disciplines, non-medical professionals (such as psychologists and biologists), and nurses and technologists. In order to acquire official accreditation by the American Academy of Sleep Medicine (1) and other national or international sleep medicine societies, such as the European Sleep Research Society (2), sleep centers must demonstrate the competence to be able to diagnose and treat all types of sleep disorders, thereby making the formation of multi-disciplinary and multi-professional teams a structural necessity.

Not only do the technical, physiological or biomedical aspects of the sleep-disordered body require the attention of professionals from various disciplines, it is also important to recognize bed-partners and/or family members as a crucial factor in the social environment of a sleep-disordered person, for example in the evaluation of a patient's sleep history (e.g. snoring, apneas, abnormal movements during sleep, parasomnias or daytime sleepiness) (3), or quality of life related questions in sleep related breathing disorders (SRBD)(4-6), or the circadian rhythms of family members of shift workers (7).

Despite the evident necessity of multi-professional, multi-disciplinary, and bio-psycho-social estimations in sleep medicine, no instrument exists that comprehensively and uniformly describes the lived experience of persons with sleep disorders.

With the adoption of the International Classification of Functioning, Disability and Health (ICF) in 2001 (8), a conceptual framework that offers a way to capture all aspects of physical, mental and social well-being became available (see overview in table 1).

Table 1: An overview of ICF (World Health Organization (WHO) 2001, p. 11)

	Part 1: Functioning and Disability		Part 2: Contextual Factors	
Components	Body Functions and Structures	Activities and Participation	Environmental Factors	Personal Factors
Domains	Body functions Body structures	Life areas (tasks, actions)	External influences on functioning and disability	Internal influences on functioning and disability
Constructs	Change in body functions (physiological) Change in body structures (anatomical)	Capacity Executing tasks in a standard environment Performance Executing tasks in the current environment	Facilitating or hindering impact of features of the physical, social, and attitudinal world	Impact of attributes of the person
Positive aspect	Functional and structural integrity	Activities Participation	Facilitators	not applicable
	Functioning			
Negative aspect	Impairment	Activity limitation Participation restriction	Barriers / hindrances	not applicable
	Disability			

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However, this catalogue of over 1400 mutually exclusively categories is too exhaustive to be feasible in daily sleep medicine practice (9-10). In daily practice, clinicians need only a fraction of the categories found in the ICF. With this need in mind, WHO and the ICF Research Branch have been developing so-called ICF Core Sets (11), which identify those areas of human functioning that are most relevant to a certain health condition or clinical setting, in this case any kind of primary sleep disorder (12). It is important to note that both the ICF and the ICF Core Sets are not measurement tools as such; they tell us 'what' to potentially measure, not 'how' to measure it. ICF does not measure disability; it describes people's functional abilities on the domains of *Body Functions & Body Structures*, *Activities & Participation*, and *Environmental Factors*. The health conditions and their manifestation properties (signs & symptoms) are classified in existing and complementary systems like the International Classification of Diseases (ICD-10) (13), the International Classification of Sleep Disorders (ICSD-2) (14), or the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) (15). Given that the latter two operate with distinct and general definitions of 'daytime impairments' as diagnostic criteria, the systematic and evidence-based specification of these functioning properties of sleep disorders seems indicated.

In line with the bio-psycho-social model of health the preparatory phase of this ICF Core Set development project explores sleep disorders from four different perspectives: the patient, clinical, researcher, and health professional perspectives (see Figure 1).

Figure 1: Development Process of ICF Core Sets for Sleep Disorders

Preparatory-Phase	Phase I	Phase II
Patient Perspective Focus Group Study **Clinical Perspective** Patient Interviews **Researcher Perspective** Literature Review **Expert Perspective** Expert Survey	**International ICF Consensus Conference** ↓ **1st Version of ICF Core Sets for Sleep Disorders**	**Implementation and Validation of 1st Version of ICF Core Sets**
2007-2009	**May 2009**	
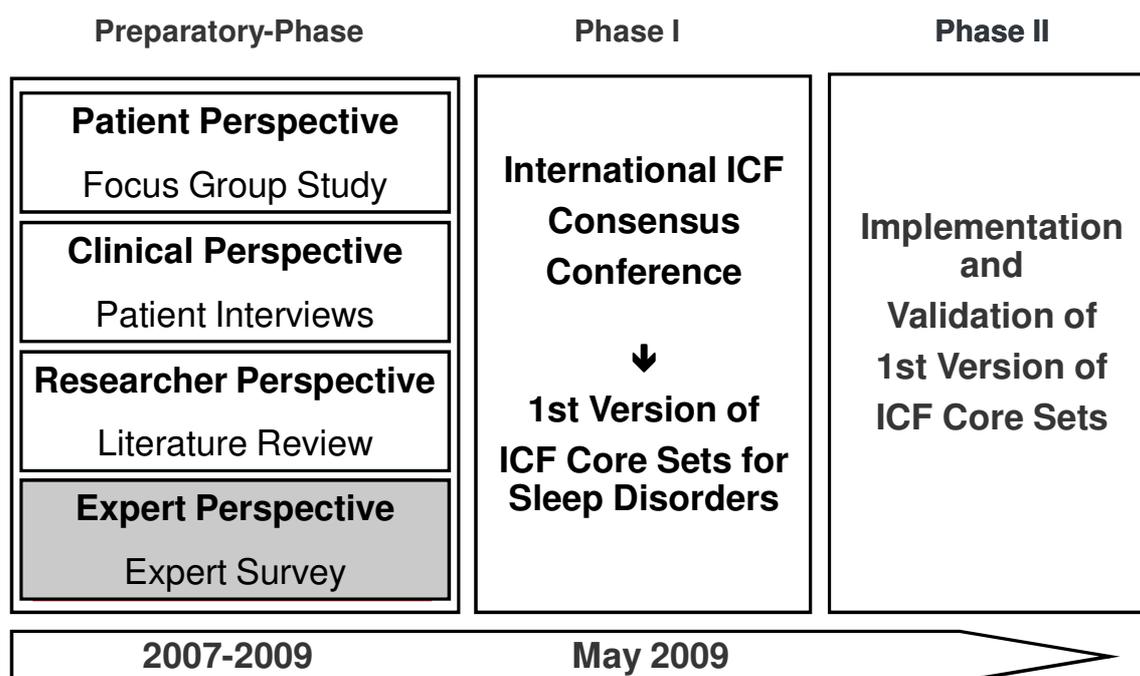
The objective of the first phase of the project (i.e. preparatory studies) is to create an evidence base for a consensus conference during which a cadre of international sleep disorder experts decide on the first version of the ICF Core Sets for Sleep Disorders (16). One of the four preparatory studies in the development of the ICF Core Sets for Sleep Disorders explores the expert perspective on sleep disorders.

Objective

The overall objective of this study is to identify relevant aspects of functioning as well as related environmental factors from the perspective of health professionals worldwide experienced in treating persons with any kind of sleep disorder.

The specific aims are (1) to identify the areas of functioning considered a problem or impairment, or environmental factors relevant from the international perspective of most professional disciplines involved in the treatment of sleep disorders, (2) to

report and quantify those areas of functioning and environmental factors using the ICF.

METHODS

Study design

The study was conducted as a worldwide email-based survey including physicians, nurses, therapists, technicians, biologists and psychologists.

Recruitment procedure and study population

Based on a comprehensive internet search of sleep specialists, sleep centres and professional organisations on local, national and international levels a list of health professionals with corresponding email-addresses was generated.

All of these health professionals were contacted (followed by a first reminder 2 weeks later and final call 2 weeks after that).

Experts had to meet the following criteria to be included in the survey: (1) the professional background had to be related to sleep medicine practice (2) at least 2 years of experience in direct contact with adult individuals with any kind of (primary) sleep disorder; (3) fluency in the English language. All health professionals who met these inclusion criteria and agreed to participate in the survey made up the so-called 'expert pool'. In a next step, a random sample was drawn out of the expert pool stratified by professional background and WHO regions [http://www.who.int/about/regions/en/index.html]. This was done to assure that the different professional perspectives as well as the regional perspectives were represented. An exception was made for the 'African Region': all nominated experts from this region were included as the number was extremely small.

Questionnaire

The questionnaire applied in the expert survey consisted of two parts.

In part I basic demographic information about the participant, the professional background, specialisation and experience was gathered.

In part II of the questionnaire, the experts were asked to list the problems in functioning as well as relevant environmental and personal factors of individuals with any kind of (primary) sleep disorder. The open-ended questions are shown in table 2.

Table 2. Questions applied in the expert survey

1. If you think about the **body and mind** of individuals with any kind of sleep disorder, what **does not work** the way it is supposed to?

2. If you think about the **body** of individuals with any kind of sleep disorder, **in which parts** are their problems?

3. If you think about the **daily life** of individuals with any kind of sleep disorder, **what** are their problems?

4. If you think about the **environment** and the **living conditions** of individuals with any kind of sleep disorder, what is **supportive** for them?

5. If you think about the **environment** and the **living conditions** of individuals with any kind of sleep disorder, what is **hindering** for them?

6. If you think about individuals with any kind of sleep disorder, what is **important** about them and the way they **handle their condition**?

Data collection procedure

The expert survey was conducted between March and July 2007. All selected experts from the expert pool received an e-mail with detailed information about the expert survey, the actual questionnaire and instructions about further procedures. Monthly reminders were sent 4 consecutive months following the initial distribution of the survey. Answers were kept anonymous by extracting the content through an Access database.

Data analysis

Two researchers (multiple coding) independently linked the statements of the participants to categories of the ICF based on established linking rules (17-18). These enable the translation of statements to ICF categories in a systematic and standardized way. According to these linking rules, researchers trained in the taxonomy of the ICF link each statement to that ICF category which most precisely represents the meaningful concept behind it. One statement could therefore be linked to one or more ICF categories, depending on the number of meaningful concepts contained in the respective statement.

If a statement or meaningful concept was too general to allow a decision on the linking to a specific ICF component, chapter (hierarchy Level 1), or category (hierarchy Level 2-4), the statement was considered as the residual code 'nd - not defined' (e.g. "limited daytime functioning"). If a statement described an aspect which

is not covered by the ICF, the code 'nc - not covered' was attributed (e.g. "risk of accidents"). Answers containing information related to health conditions (e.g. comorbidities) were coded as 'hc-health condition'.

Absolute frequencies and relative frequencies of the linked ICF categories are reported. ICF categories are presented at the second level for ease of access to the presentation. Therefore, third and fourth level ICF categories are reported at their corresponding second level only. The component 'personal factors' is not yet classified in the current version of ICF. Identified aspects of this component were coded as 'pf'.

Quality assurance procedures

All researchers involved in the data analysis were professionally trained in the content, structure and application of ICF categories and the refined linking methodology developed by the ICF Research Branch.

To ensure the reliability of the linking 40% of the respondent's statements were linked by two health professionals independently. The degree of agreement between the two health professionals regarding the linked ICF categories on the first, second and third level of ICF hierarchy was calculated by kappa statistic with bootstrapped confidence intervals using SAS (19-20).

RESULTS

Participants

Of the 1745 e-mails sent to potential participants in the initial stage of recruitment, 377 agreed to participate after two reminders. From this expert pool 174 experts were selected based on a stratified (professional background, WHO Region) and, where possible, a randomised selection. Of these, 123 experts (70.7 %) returned their completed questionnaires after the four follow-up reminders (more information on recruitment online-only).

Mean age of the participants was 49.9 years (SD 9.3) with a range from 28 to 77 years. Forty-eight (39%) were female.

The main working field of the participants was the 'clinical practice' (82%) followed by 'research', 'sleep lab', and 'education'. The mean number of years of general professional experience was 22.2 years (SD 9.6). The mean number of years of practical experience with persons with sleep disorders was 15.1 years (SD 8.5).

The participants came from all 6 WHO regions and 54 countries: 36 (29.3%) participants from countries of The Americas, 35 participants (28.4%) from the European Region, 29 (23.6%) from the Western Pacific Region, 14 (11.4%) from the Eastern Mediterranean Region, 7 (5.7%) from the South East Asia Region, and 2 (1.6%) from the African Region. The professional background of the participants is shown in table 3.

Table 3 Professional Background of participants

	Frequency	Percentage
Pulmonology	28	22.8
Neurology/Neurophysiology	23	18.7
Psychiatry	15	12.2
Psychology/Psychophysiology	15	12.2
Otolaryncology	10	8.1
Nursing	8	6.5
Physiology	7	5.7
Pediatrics	4	3.3
Pharmacology	3	2.4
Other (Circadian, Dentistry, Cardiology, Engineering, Therapist)	10	8.1
Total	123	100.0

Linking of statements

The experts mentioned 5200 themes ('meaningful concepts') which were linked to 7256 ICF categories. These 7256 linkings are represented by 189 different 2nd level ICF categories. The majority of these linkings (33.3%) were attributed to 58 different ICF categories of the ICF component body functions, followed by 21.8% of linkings to 52 categories of environmental factors, 16.1% of linkings to 49 different categories in activities & participation, and 9.7% of linkings to 29 categories of body structures. Most concepts were assigned to ICF categories at the 2nd level (n=3473, 47.9%), followed by third or fourth level categories (n=1956, 27%).

In addition, 593 (8.2%) of linkings were attributed to the ICF component, personal factors. The rest of the concepts were coded as 'nc - not classifiable' (3.4%), 'hc - health condition' (3.7%), and as 'nd - not definable' (3.8%).

Figure 2 shows all those categories mentioned by at least 20% of participants. The full result tables can be accessed online as supplementary material.

Figure 2: Most frequently identified ICF Categories

ICF

Functioning and Disability

Body Functions and Body Structures

Component + Body Functions (codes b1-b8)		33.3
Chapter 1 Mental functions (b1)		
b110	Consciousness functions	38.2*
b126	Temperament and personality functions	59.3
b130	Energy and drive functions	71.5
b134	Sleep functions	84.6
b140	Attention functions	70.7
b144	Memory functions	50.4
b152	Emotional functions	34.1
Chapter 2 Sensory functions and pain (b2)		
b280	Sensations of pain	34.1
Chapter 4 Functions of the cardiovascular, haematological, Immunological and respiratory system (b4)		
b420	Blood pressure functions	20.3
b440	Respiration functions	32.5
b455	Exercise tolerance Functions	48
Chapter 5 Functions of the digestive, metabolic and endocrine system (b5)		
b530	Weight maintenance functions	43.1
Chapter 6 Genitourinary and reproductive functions (b6)		
b640	Sexual functions	42.3

*2nd level categories in Body Functions (Percentage of experts (N=123) mentioning the respective ICF category at least once; cut-off ≥20%)

Component + Body Structures (code s s1-s8)		9.7
Chapter 1 Structures of the nervous System (s1)		
s110	Structure of brain	61*
Chapter 3 Structures involved in voice and speech (s3)		
s310	Structure of nose	22.8
s320	Structure of mouth	20.3
s330	Structure of pharynx	24.4
Chapter 4 Structures of the cardiovascular, immunological and respiratory system (s4)		
s410	Structure of cardiovascular system	42.3
s430	Structure of respiratory system	35
Chapter 7 Structures related to movement (s7)		
s710	Structure of head and neck region	22
s750	Structure of lower extremity	20.3

*2nd level ICF Categories in Body Structures (Percentage of all experts (N=123) mentioning the respective ICF category at least once; cut-off ≥20%))

Activities and Participation

Component + Activities & Participation (codes d1-d9)		16.1
Chapter 4 Mobility (d4)		
d475	Driving	57.7*
Chapter 5 Self-care (d5)		
d570	Looking after one's health	71.5
Chapter 7 Interpersonal interactions and relationships (d7)		
d770	Intimate relationships	24.4
Chapter 8 Major life areas (d8)		
d820	School education	20.3
d850	Remunerative employment	64.2
d855	Non-remunerative employment	26.8
Chapter 9 Community, social and civic life (d9)		
d920	Recreation and leisure	22

*2nd level categories in Activities & Participation (Percentage of experts (N=123) mentioning the respective ICF category at least once; cut-off ≥20%)

Contextual Factors

Environmental Factors

Component + Environmental Factors (codes e1-e5)		21.8
Chapter 1 Products and technology (e1)		
e110	Products or substances for personal consumption	51.2*
e115	Products and technology for personal use in daily living	38.2
e155	Design, constructions and building products and technology of buildings for private use	25.2
Chapter 2 Natural environment and human-made changes to environment (e2)		
e240	Light	26.8
e250	Sound	34.1
Chapter 3 Support and relationships (e3)		
e310	Immediate family	43.1
e355	Health professionals	30.9
e410	Individual attitudes of immediate family members	32.5
Chapter 5 Services, systems and policies (e5)		
e570	Social security services, systems and policies	21.1
e580	Health services, systems and policies	88.6
e590	Labour and employment services, systems and policies	36.6

*2nd level categories in Environmental Factors (Percentage of experts (N=123) mentioning the respective ICF category at least once; cut-off ≥ 20%)

Personal Factors

Component+ Personal Factors (not classified in ICF)	8.2

Residual Code+ Not defined - nd (not classified in ICF)	3.8

Residual Code+ Health condition - hc (not classified in ICF)	3.7

Residual Code+ Not classified - nc (not classified in ICF)	3.4

+ Percentage of overall number of linked concepts (n=7256) on component level

We found that Body Functions and Body Structures are equally distributed: in the component Body Functions 58 out of 80 (72.5%) existing 2nd level categories were mentioned, and the component Body Structures was elaborated through 29 categories of a total of 40 (72.5%) different 2nd level ICF categories in this component. The component Activities & Participation represented 49 2nd level categories out of 82 (59.8%) (possible) categories in this component (as a whole). Most elaborately, experts dwelt on the component Environmental Factors, where 52 out of 64 (81.2%) possible 2nd level ICF categories were identified.

Kappa

► ICF Level1 (e.g. b1 Mental functions):

Estimated Kappa Coefficient: 0.76; Asymptotic Standard Error: 0.01; Bias Corrected Percentile Method: (0.74, 0.77); Percentage of agreement: 77.63%

► ICF Level2 (e.g. b134 Sleep functions):

Estimated Kappa Coefficient: 0.70; Asymptotic Standard Error: 0.01; Bias Corrected Percentile Method: (0.69, 0.72); Percentage of agreement: 71%

► ICF Level3 (e.g. b1340 Amount of sleep):

Estimated Kappa Coefficient: 0.64; Asymptotic Standard Error: 0.01; Bias Corrected Percentile Method: (0.62, 0.66); Percentage of agreement: 64.62%

DISCUSSION

This is the first survey that explores the functional problems of individuals with sleep disorders from a worldwide perspective of the majority of the health professions involved in the treatment of these disorders. The ICF was used as reference as it provides a neutral framework and language as well as a comprehensive catalogue to describe all aspects of functioning as defined by WHO. The experts addressed a wide spectrum of aspects in functioning and health that reflect the complexity of sleep disorders.

The ICF categories identified by the experts as being relevant for persons with any kind of (primary) sleep disorder cover all of the components and almost all chapters of the ICF classification. This can be considered a well balanced and comprehensive distribution, representing the biological, psychological and social implications of sleep disorders.

Body Functions, in our sample represent those aspects of sleep-related problems which have already been consolidated through an abundance of biomedical findings, for example principal insights about cognitive functioning (e.g. sleepiness and alertness) (21). The functional impairments in the component *Body Functions* are then also reflected through known consequences of disordered sleep on *Body Structures*, like cardiovascular, cerebrovascular and metabolic aspects (22-23).

However, the experts also mentioned a range of important factors of the patient's lived experience. These cover essential aspects of health behaviour (especially sleep hygiene). Furthermore, the experts emphasized the importance of activities of daily living (ADL). This was reflected in numerous linkings to the codes specified in the ICF chapter *Major Life Areas*, like school or work.

While all the findings above reproduce well-researched aspects of the manifestation and functioning properties of many sleep disorders, new insights gained by applying the ICF model relate to the interaction of person and environment. The strengths of the comprehensive model and conceptualization of ICF can be well understood when looking at the participation categories of *Support and Relationships*. Our results show that experts gave credit to this multi-dimensional, complex and bi-directional interaction. Experts both saw an impact of the sleep disorder on relationship qualities but also the positive impact support systems like family and the health system and its representatives have on health outcomes. This is in line with evidence in research that shows that sleep patterns within families correlate (24), that sleep hygiene interventions in siblings increase overall family wellbeing (25), or that successful CPAP therapy increases quality of life in both patients and bed-partners (5).

Further important aspects of the individual health experience of patients were expressed in frequently mentioned environmental barriers related to the health system. These were captured in statements like: 'access to health care or health professional', 'diagnostic sleep testing availability', 'availability or cost of treatment, appliances, medication', 'availability of comprehensive/alternative treatment options', 'delay between symptom onset, diagnosis, and treatment', or 'access to information'.

Of the overall sample of 123 experts two remarked that they find it impossible to answer the open-ended questions for all of the different diagnostic patient groups and actually returned their questionnaires separately for the individual diagnoses.

This is a valid observation and further research could look at isolated patient groups. However some sleep patients encounter multiple sleep disorders (26-31) and must

consequently be accounted for by combined efforts and interdisciplinary strategies bringing together mind and body (32-36).

Furthermore, there might be a selection bias in our sample (377 of the 1745 responded to our initial call) that is, the questionnaire attracted those experts who are already engaged in thinking in functional terms. This is also supported by the fact that many experts belong to sleep societies. Furthermore, it is debatable whether the disciplines and their grouping give a fair representation of the wide array of professions concerned with sleep disorders. Our sample is overrepresented by experts from developed countries, a small number of psychologists, and a general lack of public health professionals, social workers and other institutional representatives.

Yet in the final sample, the relatively homogenous answers given by all the different expert groups make a point for functioning as a common denominator that cuts across diagnoses and disciplines. This finding might also be related to homologous symptoms encountered across diagnostic patient groups (e.g. sleepiness (37), tiredness (38), and fatigue(39)) which are leading to similar functional impairments (e.g. cognitive function (40), Quality of Life (41)).

This justifies the broad approach expressed by the inclusion of all professions involved in sleep medicine practice rather than concentrating exclusively on one sleep disorder or one professional group. Also, it can be considered proof of concept for the bio-psycho-social approach of the ICF to start from a comprehensive functioning perspective rather than focusing unilaterally on diagnostics and symptoms.

It would also be important to discuss the implications of having data that are dominated by a westernized perspective; experts from developing countries in southern WHO regions are underrepresented. Yet, if sleep disorders are generally underdiagnosed (42-49) and if, structurally, sleep disorders treatment is not easily accessible to the populations in westernised countries (50-53), then the same is likely to occur for the other parts of the world where such services might not be available at all. This important public health issue is being addressed by our sample through the mentioning of the corresponding environmental factors.

The above-mentioned limitations make a good starting point for further research applying larger sample sizes and comparing functional outcomes across different sleep disorders and different regions of the world.

Conclusion

This study delivered evidence for the suitability of a bio-psycho-social evaluation of sleep disorders. International specialists from different professional backgrounds involved in the clinical care of patients with sleep disorders delivered a comprehensive and balanced functioning profile of persons with any kind of sleep disorder when using the ICF framework as a reference. The ICF framework has been found to be suitable to depict and address the complexity of sleep disorders.

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Additional online-only material:

Absolute and relative frequency of second-level categories of the International Classification of Functioning, Disability and Health (ICF) linked to the themes contained in the answers of the 123 participants: component Body Functions (top five marked in bold letters).

Body Functions		No. of experts	% of experts
b110	Consciousness functions	47	38
b114	Orientation function	3	2
b117	Intellectual function	7	6
b122	Global psychosocial functions	2	2
b126	**Temperament and personality function**	**73**	**59**
b130	**Energy and drive functions**	**88**	**72**
b134	**Sleep functions**	**104**	**85**
b140	**Attention functions**	**87**	**71**
b144	**Memory functions**	**62**	**50**
b147	Psychomotor functions	17	14
b152	Emotional functions	42	34
b156	Perceptual functions	6	5
b160	Thought functions	19	15
b164	Higher-level cognitive functions	16	13
b167	Mental functions of language	1	1
b180	Experience of self and time functions	10	8
b210	Seeing functions	3	2
b220	Sensations associated with the eye and adjoining structures	1	1
b230	Hearing functions	1	1
b240	Sensations associated with hearing and vestibular functions	4	3
b270	Sensory functions related to temperature and other stimuli	3	2
b280	Sensations of pain	42	34
b330	Fluency and rhythm of speech	1	1
b410	Heart functions	9	7
b415	Blood vessel functions	4	3
b420	Blood pressure functions	25	20
b430	Haematological system functions	3	2
b435	Immunological system function	8	6
b440	Respiration functions	40	33
b445	Respiratory muscle functions	3	2
b450	Additional respiratory functions	19	15
b455	Exercise tolerance functions	59	48
b460	Sensations associated with cardiovascular and respiratory functions	11	9
b510	Ingestion functions	2	2

b515	Digestive functions	8	7
b525	Defecation functions	4	3
b530	Weight maintenance functions	53	43
b535	Sensations associated with the digestive system	9	7
b540	General metabolic functions	16	13
b545	Water, mineral and electrolyte balance functions	2	2
b550	Thermoregulatory functions	4	3
b555	Endocrine gland functions	9	7
b610	Urinary excretory functions	3	2
b620	Urination functions	19	15
b640	Sexual functions	52	42
b650	Menstruation functions	2	2
b660	Procreation functions	4	3
b670	Sensations associated with genital and reproductive functions	2	2
b730	Muscle power functions	3	2
b735	Muscle tone functions	9	7
b740	Muscle endurance functions	2	2
b760	Control of voluntary movement functions	7	6
b765	Involuntary movement functions	14	11
b770	Gait pattern functions	13	11
b780	Sensations related to muscles and movement functions	6	5
b810	Protective functions of the skin	1	1
b830	Other functions of the skin	2	2
b840	Sensations related to skin	1	1

Absolute and relative frequency of second-level categories of the International Classification of Functioning, Disability and Health (ICF) linked to the themes contained in the answers of the 123 participants: component Body Structures (top five marked in bold letters).

Body Structures		no of experts	% of experts
s110	**Structure of brain**	**75**	**61**
s120	Spinal cord and related structures	2	2
s140	Structure of sympathetic nervous system	6	5
s150	Structure of parasympathetic nervous system	5	4
s220	Structure of eyeball	3	2
s260	Structure of inner ear	1	1
s310	**Structure of nose**	**28**	**23**
s320	Structure of mouth	25	20
s330	**Structure of pharynx**	**30**	**24**

s340	Structure of larynx	8	7
s410	**Structure of cardiovascular system**	**52**	**42**
s420	Structure of immune system	3	2
s430	**Structure of respiratory system**	**43**	**35**
s520	Structure of oesophagus	4	3
s530	Structure of stomach	5	4
s540	Structure of intestine	1	1
s550	Structure of pancreas	1	1
s560	Structure of liver	1	1
s580	Structure of endocrine glands	22	18
s610	Structure of urinary system	7	6
s630	Structure of reproductive system	6	5
s710	Structure of head and neck region	27	22
s720	Structure of shoulder region	2	2
s730	Structure of upper extremity	12	10
s740	Structure of pelvic region	1	1
s750	Structure of lower extremity	25	20
s760	Structure of trunk	6	5
s770	Additional musculoskeletal structures related to movement	9	7
s810	Structures of areas of skin	3	2

Absolute and relative frequency of second-level categories of the International Classification of Functioning, Disability and Health (ICF) linked to the themes contained in the answers of the 123 participants: component Activities and Participation (top five marked in bold letters).

Activities & Participation		no of experts	% of experts
d110	Watching	6	5
d115	Listening	1	1
d130	Copying	1	1
d155	Acquiring skills	3	2
d160	Focusing attention	2	2
d166	Reading	5	4
d175	Solving problems	3	2
d177	Making decisions	5	4
d210	Undertaking a single task	3	2
d220	Undertaking multiple tasks	1	1
d230	Carrying out daily routine	20	16
d240	Handling stress and other psychological demands	18	15
d330	Speaking	1	1
d350	Conversation	1	1

d410	Changing basic body position	2	2
d415	Maintaining a body position	4	3
d450	Walking	8	7
d455	Moving around	1	1
d470	Using transportation	4	3
d475	**Driving**	**71**	**58**
d510	Washing oneself	1	1
d530	Toileting	1	1
d540	Dressing	1	1
d550	Eating	5	4
d560	Drinking	1	1
d570	**Looking after one's health**	**88**	**72**
d630	Preparing meals	2	2
d640	Doing housework	12	10
d660	Assisting others	2	2
d710	Basic interpersonal interactions	1	1
d720	Complex personal interactions	1	1
d740	Formal relationships	1	1
d750	Informal social relationships	8	7
d760	Family relationships	22	18
d770	**Intimate relationships**	**30**	**24**
d810	Informal education	8	7
d820	School education	25	20
d825	Vocational training	8	7
d830	Higher education	12	10
d845	Acquiring, keeping and terminating a job	23	19
d850	**Remunerative employment**	**79**	**64**
d855	**Non-renumerative employment**	**33**	**27**
d870	Economic self-sufficiency	19	15
d910	Community life	16	13
d920	Recreation and leisure	27	22
d940	Human rights	2	2

Relative frequency of second-level categories of the International Classification of Functioning, Disability and Health (ICF) linked to the themes contained in the answers of the 123 participants: component Environmental Factors (top five marked in bold letters).

Environmental Factors	no of experts	% of experts
e110 **Products or substances for personal consumption**	**63**	**51**
e115 **Products and technology for personal use in daily living**	**47**	**38**

e120	Products and technology for personal indoor and outdoor mobility	1	1
e125	Products and technology for communication	4	3
e140	Products and technology for culture, recreation and sport	1	1
e150	Design, construction and building products and technology for public use	3	2
e155	Design, construction and building products and technology for private use	31	25
e160	Products and technology of land development	1	1
e165	Assets	2	2
e210	Physical geography	1	1
e215	Population	3	2
e220	Flora and fauna	2	1
e225	Climate	14	11
e235	Human-caused events	1	1
e240	Light	33	27
e245	Time-related changes	11	9
e250	Sound	42	34
e255	Vibration	1	1
e260	Air quality	7	6
e310	**Immediate family**	**53**	**43**
e315	Extended family	8	7
e320	Friends	5	4
e325	Acquaintances, peers colleagues, neighbours and community members	15	12
e330	People in positions of authority	6	5
e340	Personal care providers and personal assistants	1	1
e350	Domesticated animals	3	2
e355	Health professionals	38	31
e410	Individual attitudes of immdiate family members	40	33
e415	Individual attitudes of extended family members	5	4
e420	Individual attitudes of friends	7	6
e425	Indiviudal attitudes of acquaintances, peers colleagues, neighbours	3	2
e430	Individual attitudes of people in positions of authority	5	4
e450	Individual attitudes of health professionals	13	11
e455	Individual attitudes of health-related professionals	1	1
e460	Societal attitudes	23	19
e465	Social norms, practices and ideologies	9	7
e510	Services, systems and policies for the production of consumer goods	2	2
e535	Communication services, systems and policies	1	1
e540	Transporation services, systems and policies	5	4
e545	Civil protection services, systems and policies	2	2
e550	Legal services, systems and policies	2	2
e555	Associations and organizational services, systems and policies	13	11

e560	Media services, systems and policies	5	4
e565	Economic services, systems and policies	4	3
e570	Social security services, systems and policies	26	21
e575	General social support services, systems and policies	9	7
e580	**Health services, systems and policies**	**109**	**89**
e585	Education and training services, systems and policies	20	16
e590	**Labour and employment services, systems and policies**	**45**	**37**
e595	Political services, systems and policies	2	2

Recruitment Procedure:

Date	Mails Sent	Returned/ out of office/spam/other	Refusal	Consent/ Completed
First Contact 13/03/07	1745	354 (64 verified)	55	196
First Reminder 27/03/07	1269	108	54	123
Final Call 13/04/07	889	154	18	58
Total			127	**377**
Questionnaire first contact 24/04/07	174	3	0	70
Questionnaire first reminder 21/05/07	104	0	1	36
Questionnaire second reminder 11/06/07	71	6	5	7
Questionnaire second round 03/07/07	20	3	0	5
Questionnaire second round reminder 01/08/07	14	6	2	5
TOTAL	**383**	**18**	**8**	**123**

Numbers of experts that consented to participate in the survey:

	Pulmonology/Enterology	Neurology/Neurophysiology/Neurosciences/Psychiatry	Psychology/Psychophysiology	Physiology/Clinician/Sleep Lab/Pediatrics	Otolaryncology/Dentistry	Nurses/Therapists	Other: Pharma, Business, Technicians	Total
Europe	41	82	9	37	8	2	3	**182**
America	11	45	15	34	1	9	3	**118**
Western Pacific	8	15	7	8	1	3	1	**43**
South-Eastern Asia	4	1	0	4	0	0	3	**12**
Eastern Mediterranean	3	5	0	10	0	0	0	**18**
Africa	1	1	0	1	0	0	1	**4**
Total	**68**	**152**	**31**	**94**	**10**	**14**	**11**	**377**

Numbers of experts that completed the survey:

	Pulmonology/Enterology	Neurology/Neurophysiology/Neurosciences/Psychiatry	Psychology/Psychophysiology	Physiology/Clinician/Sleep Lab/Pediatrics	Otolaryncology/Dentistry	Nurses/Therapists	Other: Pharma, Business, Technicians	Total
Europe	6	8	6	5	8	1	1	**35**
America	8	6	6	7	1	6	2	**36**
Western Pacific	5	11	4	6	1	2		**29**
South-Eastern Asia	2			3			2	**7**
Eastern Mediterranean	3	7		4				**14**
Africa		1					1	**2**
Total	**24**	**33**	**16**	**25**	**10**	**9**	**6**	**123**

International Classification of Functioning, Disability and Health (ICF) - ICF Core Sets for Persons with Sleep Disorders: Results of the Consensus Process integrating Evidence from Preparatory Studies

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Abstract

Background/Objectives

The International Classification of Functioning, Disability and Health provides a comprehensive and universally accepted framework to classify changes in functioning related to health conditions. Comprehensive and Brief Core Sets have been defined for various disorders but not for sleep disorders. Such a Core Set would greatly enhance the techniques available to describe the impact of sleep disorders on patients. The overarching purpose of this paper is to report on phase 1 of the international and WHO endorsed consensus process in identifying ICF Core Sets for Sleep Disorders.

Methods

A formal decision-making and consensus process which integrated evidence gathered from preparatory studies was carried out. Relevant ICF categories were selected by a sample of international experts from different backgrounds using the nominal group technique.

Results

Twenty-six experts from 22 countries and different professional backgrounds attended the consensus conference. Altogether 120 second- or third-level ICF categories were included in the Comprehensive ICF Core Set with the following ICF component split: 49 categories from body functions, 8 from body structures, 31 from activities and participation and 32 from environmental factors. The Brief ICF Core Set included a total of 15 second-level categories: 5 body functions (sleep, energy and drive, attention, consciousness, respiration functions); 3 body structures (brain, respiratory system, pharynx); 4 activities and participation (focusing attention, driving, handling stress and other psychological demands, carrying out daily routine); and 3 environmental factors (immediate family, health services, systems, and policies, and health professionals).

Conclusion

A formal consensus process integrating evidence and expert opinion led to the first version of the ICF Core Sets for persons with sleep disorders. Further validation of the Core Set is needed.

INTRODUCTION

Sleep disorders, be they primary or secondary, are of major interest to public health (1). The National Institutes of Health estimates that 50 to 70 million Americans chronically suffer from disorders of sleep and wakefulness. The 2nd edition of the International Classification of Sleep Disorders (ICSD-2)(2) distinguishes over eighty different sleep disorder diagnoses. The six major categories of this classification are the following: Insomnia, Sleep Related Breathing Disorders, Hypersomnias of Central Origin, Circadian Rhythm Sleep Disorders, Parasomnias, and Sleep Related Movement Disorders.

A common factor to all these sleep disorders is a significant negative impact on the daily lives of the people and their families. Aspects of human functioning in various sleep disorders have been extensively researched, including school functioning (3-4), work disability (5), and driving (6). The impact of sleep disorders could also be seen to affect the social environment and personal activities through bedpartners/co-sleeping (7-10) relationships (11-13) and sexual functions (14). In order to assess the impact of these sleep disorders many different measures focusing on different areas have been developed.

However, a single comprehensive functional description of these and other factors related to sleep function is not available. For clinical practice and research it would be desirable to have an applicable framework that covers the entire spectrum of disabilities that reflect the patient's total lived experience with sleep disorders. Furthermore, shared terminology and common definitions would be helpful in the multi-disciplinary approaches of sleep medicine practice.

The International Classification of Functioning, Disability and Health (ICF), which is like the International Classification of Diseases-10th revision (ICD-10)(15) one of the official classifications of WHO, provides a comprehensive and universally accepted framework to classify and describe functioning, disability and health in people with all kinds of diseases or conditions or health states, regardless of aetiology. It tries to provide a scientific basis for the consequences of health conditions, to establish a common language to improve communications, to permit comparisons of data across countries, health care disciplines, services, and to provide a systematic coding scheme for health information systems.

ICF adds to the predominant linearization from the disease perspective of the ICD-10 an integrative and comprehensive perspective that synchronizes functional problems

associated with health conditions. ICF furthermore shifts the focus from cause to impact. It therefore posits all health conditions on an equal footing and allows them to be compared using a common framework - the metric of functioning, disability and health ((16), p. 7-9).

The ICF can be divided into two parts. The first part covers functioning and disability and includes the components *Body (or physiological) Functions* (coded as b), *Body (or anatomical) Structures* (coded:s), and *Activities and Participation* (coded: d). The second part covers the contextual factors, namely *Environmental* (coded: e) and *Personal Factors* (not yet coded in ICF). In the ICF classification, the letters b, s, d and e are followed by a numeric code starting with the chapter number (one digit) followed by the second (two digits), third, and fourth levels (one additional digit each)(17)

Figure 1: Structure of the ICF (WHO, 2001; the figure has been reprinted with permission of the WHO, all rights are reserved by the Organization)
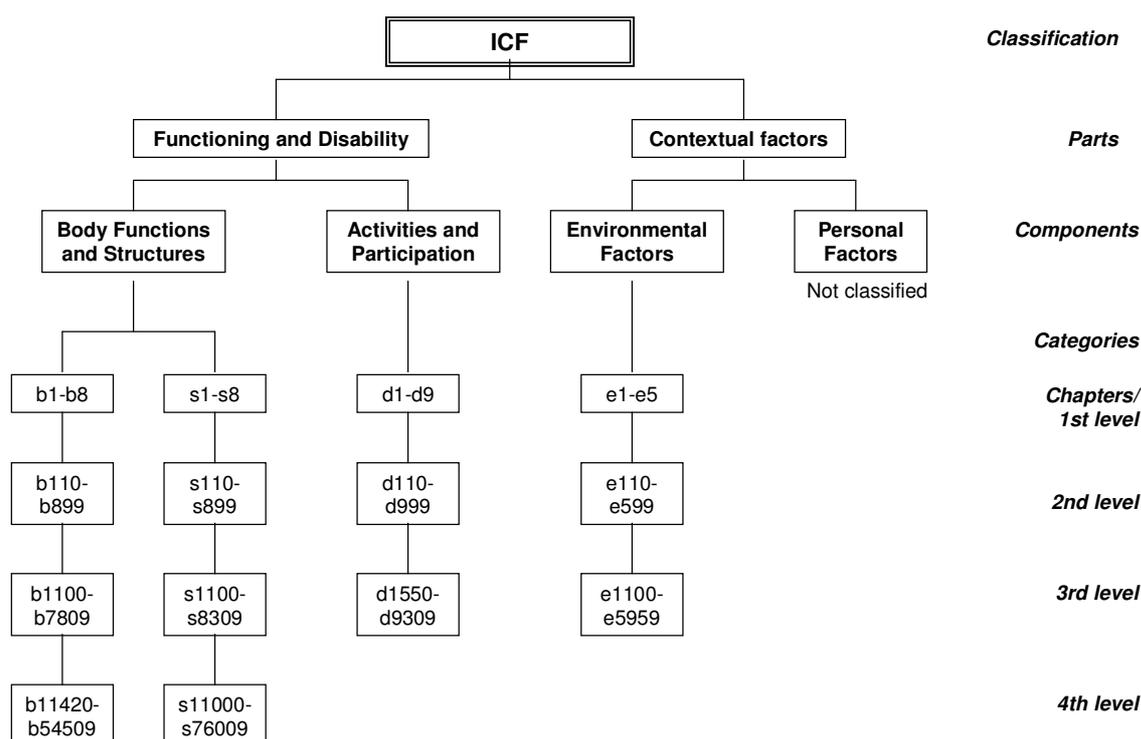
Overall, including the lower third and fourth levels, the ICF presents 1424 comprehensive categories. In order to make this classification feasible in practice, a reduction or selection of these categories relevant for a specific health condition is

required. Both brief and comprehensive lists, or ICF Core Sets (18), have been developed for 18 different health conditions including depression (19), obesity (20), obstructive pulmonary disease (21), stroke (22) chronic ischemic heart disease (23), and diabetes mellitus (24).

The Brief ICF Core Set is defined as a minimal standard to describe functioning in any clinical setting and research endeavour and the Comprehensive ICF Core Set is described as standard to be used in any comprehensive assessment involving different professions.

Therefore, with the endorsement of the Classification, Assessment and Terminology team at the World Health Organization (WHO) and the World Association of Sleep Medicine (WASM), the aim of this project was to develop Brief and Comprehensive ICF Core Sets for Sleep Disorders. The development process of the ICF Core Sets consisted of a preparatory phase where we gathered information from four different studies, and a final consensus conference (25). The project was coordinated by the ICF Research Branch of the Collaborating Centre for the WHO Family of International Classifications (FIC) in German. The objective of this paper is to report on the results of the consensus process in developing the Comprehensive and Brief ICF Core Set for Sleep Disorders.

METHODS

The process was started with four preparatory studies. These preparatory studies helped pre-select ICF categories that were relevant to persons with any kind of sleep disorder from four different perspectives: (1) The patient or consumer perspective, was captured through focus groups with 6 predefined open questions relating to the ICF components (26). (2) The health professional perspective was explored with an expert survey using the same questions as those used for the patient focus groups. (3) The clinical perspective was obtained and explored with an empirical multi-centre study at 3 different centers in Switzerland, where the ICF was used to identify problems in functioning in persons with sleep disorders. (4) Finally, the perspective of researchers was covered by a systematic literature review identifying questionnaires used in sleep medicine practice and research (27). The patient studies were approved by the ethics committees in charge of the respective study centres involved (Records for Berne: 279/07; Zurich: E-37/2008; Aargau: 2008/064). The ICF

categories selected in each of these four preparatory studies made up the starting point of the decision-making and consensus process.

Conference participants

The recruitment strategy for participants to attend the conference sought to balance the needs for international expertise without compromising a feasible decision-making process. The main inclusion criterion was direct contact with patients with any kind of sleep disorders for at least 2 years. Potential conference participants were derived from the pool of candidates that had participated in the expert survey of the preparatory studies. In addition, health professionals who had expressed their interest in the project in advance as well as people who were suggested by the project steering committee were added to the pool of potential participants. A total number of 381 names were collected from the following professional backgrounds [Pulmonology, Internal Medicine, Neurology, Neuropyhsiology, Neurosciences, Psychiatry, Psychology, Psychophysiology, Physiology, Clinicians, Pediatrics, Otolaryncology, Dentists, Nurses, Therapists, Pharmacology, Chronobiology] and 56 countries in all 6 WHO world regions. A random sample of the total pool was drawn, taking all available professions and world regions into account. If an invitee rejected the invitation or did not answer to the invitation within a certain period, an additional person with the same profession and belonging to the same world region was selected and invited.

Consensus Procedure

The participants worked actively together for 3 days in a Delphi-type teamwork technique called the Nominal Group Technique (28). The process was conducted in English language. At the beginning of the conference, participants were trained in the structure, principles, and nomenclature of the ICF. They reviewed the results from the preparatory studies; and were oriented to the principles and rules of the consensus process applied during the conference.

Categories to be included in the ICF Core Sets were chosen in two different types of sessions: working groups and plenary sessions (see figure in online supplement). Participants were divided into 3 working groups consisting of a balanced number of voting participants, including a working group leader (co-authors AB, AR, AO). During the working group sessions individual group votes on whether each ICF category should be included in the Comprehensive Core Set were counted. A nonvoting

assistant was assigned to each working group to document group results. In the plenary sessions, group votes were presented and arguments for and against the ICF categories for which they had voted were entertained from all participants. The plenary sessions were moderated by an independent health professional (AC) with experience in the ICF but without any personal involvement in sleep disorder treatment and rehabilitation and that had no right to vote.

The decision-making process included 3 consecutive steps: (1) selection of ICF categories for the Comprehensive ICF Core Set on the second level; (2) selection of categories that require further specification at lower hierarchical ICF-levels, i.e., third and fourth level; and (3) selection of categories out of the Comprehensive ICF Core Set that should be included in the Brief ICF Core Set for Sleep Disorders.

The categories for the Brief ICF Core Set for Sleep Disorders were chosen from the previously selected Comprehensive ICF Core Set by means of a ranking exercise. The cut-off for the ranking was determined in a separate vote after the ranking. Throughout the conference, the data resulting from the voting and ranking processes were fed into and processed using MS Excel 2003

RESULTS

In the empirical study 148 different second-level categories were identified. The expert survey, the qualitative study, and the systematic review yielded 189, 168 and 133 second-level categories, respectively. The preparatory studies selected a total of 227 different 2nd level categories.

The ICF Consensus Conference took place from May 28th to 30th 2009 at the ICF Research Branch of the Swiss Paraplegic Research Centre, Nottwil, Switzerland. Twenty-six experts from 22 countries and different professional backgrounds (4 Physiology, 4 Neurology, 4 Psychiatry, 4 Pulmonology, 3 Nursing, 2 Chronobiology, 2 Internal Medicine, 1 Neuropsychology, 1 Neurophysiology, 1 Neuropsychiatry) attended the consensus conference.

Comprehensive ICF Core Set

The ICF categories selected to comprise the Comprehensive ICF Core Set are shown in table 1. The number of second-, and third-level categories in the Comprehensive ICF Core Set selected was 120, with 95 categories on the second level and 25 categories on the third level derived from 6 categories on the second

level. The 120 categories of the Comprehensive ICF Core Set are made up of 49 (40.8 %) categories from the component *Body Functions*, 8 (6.7 %) from the component *Body Structures*, 31 (25.8%) from the component *Activities and Participation*, and 32 (26.7 %) from the component *Environmental Factors*.

Table 1: Comprehensive ICF Core Set for Sleep Disorders

Component	Body functions
Chapter 1	Mental functions
b110	*Consciousness functions*
b1100	*State of consciousness*
b1101	*Continuity of consciousness*
b1102	*Quality of consciousness*
b114	*Orientation functions*
b117	*Intellectual functions*
b126	*Temperament and personality functions*
b1300	*Energy level*
b1301	*Motivation*
b1302	*Appetite*
b1303	*Craving*
b1304	*Impulse control*
b1340	*Amount of sleep*
b1341	*Onset of sleep*
b1342	*Maintenance of sleep*
b1343	*Quality of sleep*
b1344	*Functions involving the sleep cycle*
b1348	*Sleep functions, other specified*
b140	*Attention functions*
b144	*Memory functions*
b147	*Psychomotor functions*
b152	*Emotional functions*
b156	*Perceptual functions*
b160	*Thought functions*
b164	*Higher-level cognitive functions*
b180	*Experience of self and time functions*
Chapter 2	Sensory functions and pain
b270	*Sensory functions related to temperature and other stimuli*
b280	*Sensation of pain*
Chapter 4	Functions of the cardiovascular, immunological, and respiratory systems
b410	*Heart functions*

b420	*Blood pressure functions*
b435	*Immunological system functions*
b440	*Respiration functions*
b445	*Respiratory muscle functions*
b450	*Additional respiratory functions*
b455	*Exercise tolerance functions*
b460	*Sensations associated with cardiovascular and respiratory functions*
Chapter 5	Functions of the digestive, metabolic and endocrine systems
b530	*Weight maintenance functions*
b540	*General metabolic functions*
b550	*Thermoregulatory functions*
b555	*Endocrine gland functions*
Chapter 6	Genitourinary and reproductive functions
b620	*Urination functions*
b640	*Sexual functions*
Chapter 7	Neuromusculoskeletal and movement-related functions
b735	*Muscle tone functions*
b7650	*Involuntary contractions of muscles*
b7652	*Tics and mannerisms*
b7653	*Stereotypies and motor perseveration*
b7658	*Involuntary movement functions, other specified*
b780	*Sensations related to muscles and movement functions*
Chapter 8	Functions of the skin and related structures
b840	*Sensation related to the skin*
Component	***Body Structures***
Chapter 1	Structures of the nervous system
s110	*Structure of brain*
Chapter 3	Structures involved in voice and speech
s310	*Structure of nose*
s320	*Structure of mouth*
s330	*Structure of pharynx*
Chapter 4	Structures of the cardiovascular, immunological, and respiratory systems
s410	*Structure of cardiovascular system*
s430	*Structure of respiratory system*
Chapter 5	Structures related to the digestive, metabolic and endocrine systems
s580	*Structure of endocrine glands*
Chapter 7	Structures related to movement
s710	*Structure of head and neck region*
Component	***Activities and participation***
Chapter 1	Learning and applying knowledge
d155	*Acquiring skills*

d160	*Focusing attention*
d166	*Reading*
d175	*Solving problems*
d177	*Making decisions*
Chapter 2	General tasks and demands
d220	*Undertaking multiple tasks*
d230	*Carrying out daily routine*
d240	*Handling stress and other psychological demands*
Chapter 3	Communication
d350	*Conversation*
Chapter 4	Mobility
d415	*Maintaining a body position*
d470	*Using transportation*
d475	*Driving*
Chapter 5	Self-care
d5700	*Ensuring one's physical comfort*
d5701	*Managing diet and fitness*
d5702	*Maintaining one's health*
Chapter 6	Domestic life
d640	*Doing housework*
d660	*Assisting others*
Chapter 7	Interpersonal interactions and relationships
d710	*Basic interpersonal interactions*
d720	*Complex interpersonal interactions*
d740	*Formal relationships*
d750	*Informal social relationships*
d760	*Family relationships*
d770	*Intimate relationships*
Chapter 8	Major life areas
d820	*School education*
d825	*Vocational training*
d830	*Higher education*
d845	*Acquiring, keeping and terminating a job*
d850	*Remunerative employment*
d855	*Non-remunerative employment*
Chapter 9	Community, social and civic life
d910	*Community life*
d920	*Recreation and leisure*
Component	**Environmental factors**
Chapter 1	Products and technology
e1100	*Food*
e1101	*Drugs*

e1150	*General products and technology for personal use in daily living*
e1151	*Assistive products and technology for personal use in daily living*
e165	*Assets*
Chapter 2	Natural environment and human-made changes to environment
e215	*Population*
e225	*Climate*
e235	*Human-caused events*
e240	*Light*
e245	*Time-related changes*
e250	*Sound*
e260	*Air quality*
Chapter 3	Support and relationships
e310	*Immediate family*
e315	*Extended family*
e325	*Acquaintances, peers, colleagues, neighbours and community members*
e330	*People in positions of authority*
e355	*Health professionals*
Chapter 4	Attitudes
e410	*Individual attitudes of immediate family members*
e425	*Individual attitudes of acquaintances, peers, colleagues, neighbours and community members*
e430	*Individual attitudes of people in positions of authority*
e440	*Individual attitudes of personal care providers and personal assistants*
e450	*Individual attitudes of health professionals*
e455	*Individual attitudes of health-related professionals*
e460	*Societal attitudes*
e465	*Social norms, practices and ideologies*
Chapter 5	Services, systems and policies
e540	*Transportation services, systems and policies*
e550	*Legal services, systems and policies*
e555	*Associations and organizational services, systems and policies*
e570	*Social security services, systems and policies*
e580	*Health services, systems and policies*
e585	*Education and training services, systems and policies*
e590	*Labour and employment services, systems and policies*

The following chapters were excluded from the comprehensive ICF Core Set: chapter 3 of *Body Functions*: V*oice and speech functions*, from *Body Structures* chapter 2 *The eye, ear and related structures*, chapter 6 *Structures related to the genitourinary and reproductive systems* and chapter 8 *Skin and related structures*.

Brief ICF Core Set

Table 2 shows the second-level ICF categories ordered by rank that were selected for the Brief ICF Core Set.

ICF code	Title
Component	**Body Functions**
b134	**Sleep functions**
b130	**Energy and drive functions**
b140	**Attention functions**
b110	**Consciousness functions**
b440	**Respiration functions**
Component	**Body Structures**
s110	**Structure of brain**
s430	**Structure of respiratory system**
s330	**Structure of pharynx**
Component	**Activities & Participation**
d160	**Focusing attention**
d475	**Driving**
d240	**Handling stress and other psychological demands**
d230	**Carrying out daily routine**
Component	**Environmental Factors**
e310	**Immediate family**
e580	**Health services, systems and policies**
e355	**Health professionals**

DISCUSSION

The formal consensus process which integrated evidence from the four preparatory studies and expert appraisal at a Consensus Conference led to the development of the first version of both Brief and Comprehensive ICF Core Sets for Sleep Disorders.

It is important to note that the ICF Core Sets for Sleep Disorders are not meant to be used a health status measure. In principle, they are a comprehensive agreed-on list of aspects that are relevant for the given health condition. They are intended as an international standard of what to measure and report but not how to measure it. The Core Sets also aim to facilitate the interpretation and aggregation of data for health information. They can further be seen as a framework to guide comprehensive, multidisciplinary follow-up and treatment.

Several functioning-related instruments for sleep disorders are validated and ready-to use, for example: Functional Outcomes of Sleep Questionnaire (29-30), Patient-Reported Outcomes Measurement System (PROMIS) Item bank: Sleep/Wake Disturbance (National Institute of Health) (31), Calgary Sleep Apnea Quality of Life Index (32), and the Pittsburgh Sleep Quality Index (33-35). However, these questionnaires either address a single sleep disorder or a selected group of aspects related to daytime functioning. These questionnaires are likely, therefore to cover some, but not all, of the aspects covered in the Comprehensive ICF Core Sets for Sleep Disorders (36-37). Thus, the ICF Core Sets can be used as a guide to developing questionnaires which are more comprehensive.

In terms of the selection of health status measures (38), the Core Sets provide added value by allowing comparison of the aspects covered by any measurement tool to the comprehensive list of the ICF Core Set, thus indicating areas missing from the individual questionnaires. Using the ICF as a guideline, the application of a given health status measure and its place in the management process of a patient with a sleep disorder can be assessed. ICF Core Sets can also be used to rate the content validity of health status measures and, thereby, select appropriate instruments for the specific needs of the patient or a certain purpose (27, 37). By standardizing the underlying functional concepts the ICF Core Set can be used to compare different measurement tools.

The 120 categories that were included in the Comprehensive Core Set reflect the wide range of functional issues that are encountered in people with sleep disorders.

Since the Core Set should be able to be applied to any kind of primary sleep disorder a wide array of functional aspects was included in the Comprehensive Core Set, ranging from cell (e.g. structures of the brain) to society (e.g. societal attitudes). The criteria adopted for inclusion in the Comprehensive ICF Core Set was that it should include as many categories as necessary to comprehensively describe functioning in patients with sleep disorders, but as few as possible to be practical. Thus some categories were included that were only valid for one particular sleep disorder, so, structure of the pharynx may only be important for obstructive sleep apnea or other types of sleep related breathing disorders. Validation of the Core Set or a portion thereof for each type of sleep disorder may be necessary and may create a separate subset of the Comprehensive Core Set for obstructive sleep apnea, narcolepsy and insomnia or possibly even more.

As part of the difficulty of creating a Core Set that would be valid for all sleep disorders, there were some categories excluded that were requested by some participants but not by a majority. If interested to know more, go to the online-only supplementary tables for an in-depth discussion of additional categories and those categories excluded.

During the conference the participants frequently remarked, that the ICF Category definitions were unclear, too general or even overlapping. This has partly to do with the complexity and comprehensiveness of the classification. It also reflects the challenge of adopting a classification system that applies a universalistic and etiologically neutral way of wording that seeks to be applicable worldwide in various settings and by various professionals. The participating experts also sought to counter this structural problem of ICF by making concrete suggestions for additional 'other specified' categories (see online-only tables), that might be considered for inclusion in the update of ICF.

Furthermore, many categories are included in the Core Set on the second level of specification regardless of what information is included in the subcategories of the classification system. This represents a major challenge to a valid evaluation of functioning domains using the ICF Core Sets for Sleep Disorders. Further research that seeks to operationalise the ICF categories and ICF qualifiers is ongoing (39-41).

It is also possible that another group of experts in sleep disorders may come up with a slightly different version of Core Sets. The selection of experts participating in this consensus conference was characterized by a lack of representatives from patient

organisations and other disciplines involved in sleep medicine like, obstetrics/gynaecologists, public health, epidemiologists, sports medicine, and nutritionists. However, these groups did not respond to the original request for involvement and could therefore not be artificially inserted into the consensus conference. It would be useful for representatives from these groups to use and suggest changes to the ICF Core Sets for Sleep Disorders.

The development of a globally acceptable frame of reference to comprehensively describe changes in functioning in patients with sleep disorders is a huge task requiring several small, incremental steps. The first step is to define which aspects of functioning should be assessed. In the format of the ICF Core Sets for Sleep Disorders and through the means of a consensus conference we now have a first version of such a list of relevant aspects. These categories selected so far still need further validation for which an international multi-centre collaborative study might be beneficial. Another future work perhaps would be to look at the validity of clustering sleep disorders into a single value set of ICF categories, and including other disciplines related to sleep medicine.

In conclusion, the development of a first version of ICF Core Sets for Sleep Disorders is the first step in the creation of an internationally accepted and standardized tool for the assessment of functional impairment and disability in patients with sleep disorders. Establishing standardized ICF Core Sets for Sleep Disorders which could assist in the development of better assessment tools would be helpful for clinical practice, teaching, medical research, and patient care.

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<u>Supplementary Online Material:</u>

***Comprehensive ICF Core Set*: List of ICF categories that includes as few categories as possible to be practical, but as many as necessary to describe the aspects of functioning relevant to persons with sleep disorders in a comprehensive, multi-disciplinary assessment**

***Brief ICF Core Set*: The fewest ICF categories that serve as minimal standard to be used internationally for the reporting of functioning in persons with sleep disorders in any care setting and across sectors (health, education, labour and social affairs) - MINIMAL DATA SET**

***Diving:* The additional specification of a 3rd level category is essential to describe the aspects of functioning relevant to patients with sleep disorders in a comprehensive, multidisciplinary assessment.**

After including candidate categories for the Comprehensive ICF Core Set for Sleep Disorders on the second level (plenary session 2), we asked participants to specify and select those categories where they saw a need to 'dive' (plenary session 3). Participants would 'dive' deeper on the selected categories onto a third level category in working group session 3 and then decide on those sub-categories that remained ambiguous in plenary session 4.

ICF Component: Body Functions (b)			
ICF Chapter: Mental Functions (b1)			
2nd level ICF Category	3rd level category	Number of yes votes in plenary session (n=26)	Arguments collected in plenary session 3 and 4
b110 Consciousness functions *General mental functions of the state of*		23 (decision to dive in plenary session 3) 23 (decision to keep 2nd level category in plenary session 4)	keeping the second level would allow it to function as a kind of summarizing category, These categories relate to waking functions in general

awareness and alertness, including the clarity and continuity of the wakeful state.	b1100 State of consciousness	24 (included in plenary session 4)	Essential to distinguish between state and continuity of consciousness
	b1101 Continuity of consciousness	Included in working group session 3 votes	Relevant in cases of automatic behaviour and intrusion of sleepiness in wakeful state
	b1102 Quality of consciousness	25 (included in plenary session 4)	Insomnia patients report their quality of consciousness to be impaired, Narcolepsy patients on stimulants report side effects here,
b130 Energy and drive functions *General mental functions of physiological and psychological mechanisms that cause the individual to move towards satisfying specific needs and general goals in a*		22 (decision to dive in plenary session 3) 1 (decision to exclude 2nd level category in plenary session 4)	Essential and specific categories, subcategories capture distinct dimensions, Evidence from preparatory studies distinguish these categories, Daytime correlate of impaired sleep function
	b1300 Energy level	Included in working group session 3 votes	In Insomnia need to distinguish between energy and fatigue
	b1301 Motivation	Included in working group session 3 votes	Motivation dependent on sleep deprivation, Addiction and motivation need to be separated, Motivation not captured anywhere else
	b1302 Appetite	Included in working group session 3 votes	Appetite regulation is related to hypocretin/orexin and sleep deprivation

persistent manner.	b1303 Craving	Included in working group session 3 votes	Relevant in sleep loss, Distinction between substance-users and non-users critical, Urge to use alcohol is driven by whether you can sleep or not
	b1304 Impulse control	25 (included in plenary session 4)	Can be a side effect in patients treated with dopaminergic drugs, Sleep deprivation will impair frontal lobe function which will impair impulse control
b134 Sleep functions *General mental functions of periodic, reversible and selective physical and mental disengagement from one's immediate environment accompanied by characteristic physiological changes.*		23 (decision to dive in plenary session 3) 4 (decision to exclude 2nd level category in plenary session 4)	Items do not seem overly practical or containing all the concepts that clinicians need
	b1340 Amount of sleep	Included in working group session 3 votes	No arguments recorded *Category Definition: Mental functions involved in the time spent in the state of sleep in the diurnal cycle or circadian rhythm.*
	b1341 Onset of sleep	Included in working group session 3 votes	No arguments recorded *Category Definition: Mental functions that produce the transition between wakefulness and sleep.*
	b1342 Maintenance of sleep	Included in working group session 3 votes	No arguments recorded *Category Definition: Mental functions that sustain the state of being asleep.*
	b1343 Quality of sleep	Included in working group	No arguments recorded *Category Definition: Mental*

		session 3 votes	*functions that produce the natural sleep leading to optimal physical and mental rest and relaxation.*
	b1344 Functions involving the sleep cycle	Included in working group session 3 votes	No arguments recorded *Category Definition: Mental functions that produce rapid eye movement (REM) sleep (associated with dreaming) and non-rapid eye movement sleep (NREM) (characterized by the traditional concept of sleep as a time of decreased physiological and psychological activity).*
	b1348 Sleep functions, other specified	Included in working group session 3 votes	Arguments see below:
Additional 'other specified' categories (b1348)*	b1348 Timing of sleep	26 (included as recommended additional category)	need to have a distinct category from *b1341 Onset of sleep*, accounting for both intrinsic (1) and extrinsic (2) circadian factors affecting sleep
	b1348 Offset of sleep including waking from sleep/terminati on of sleep	25 (included as recommended additional category)	to complete the logical sequencing and assessment of the two-process model of sleep (3), to help describe more thoroughly sleep disorders like, e.g. Idiopathic Hypersomnia (4-5)
	b1348 Persistent pattern of sleep	6 (excluded)	ICF seeks to represent a snapshot assessment only but for assessment of insomnia quality of sleep over periods of time (e.g. one month) is essential, might not need it in Sleep Apnea,

			you could do multiple assessments over time to see differences in functioning
	b1348 Napping	No vote (excluded)	Napping as additional period of sleep which is necessary to have an equilibrium over 24hrs, covered under sleep timing and sleep duration, 'napping' is a positive resource/strategy or activity rather than impaired sleep function and would be included under the category *d570 Looking after one's health* [sleep hygiene],
ICF Chapter: Neuromusculoskeletal and movement-related functions (b7)			
b765 Involuntary movement functions *Functions of unintentional, non- or semi-purposive involuntary contractions of a muscle or group of muscles.*		15 (decision to dive in plenary session 3) 7 (decision to exclude 2nd level category in plenary session 4)	Unclear whether sleep seizures are covered in this category, Need to highlight definitions in those sub-categories that are specific to sleep and skip the others
	b7650 Involuntary contractions of muscles	Included in working group session 3 votes	No arguments recorded *Category Inclusions: impairments such as choreatic and athetotic movements; sleep-related movement disorders*
	b7651 Tremor	3 (excluded in plenary session 4)	No arguments recorded
	b7652 Tics and mannerisms	Included in working group session 3	No arguments recorded *Category Inclusions: impairments such as vocal tics, coprolalia and*

		votes	*bruxism*
	b7653 Stereotypies and motor preservation	22 (included in plenary session 4)	No arguments recorded
	b7658 Involuntary movement functions, other specified	26 (included in plenary session 4)	Automatism and sleepwalking is not specified in any of the other subcategories REM sleep behavior disorders (RBDs) are not specified either
*Additional 'other specified' categories (b7658)**	b7658 Sleep-related complex behaviours	included as recommended additional category	including automatism (6), sleep seizure (7), sleep paralysis (8), sleep-walking and other parasomnias (9), need for further specification for these overlapping phenomena related to involuntary movement functions.

*Additional Categories:

'Other specified'-categories allow for the coding of aspects of functioning that are not included within any of the other specific sub-categories. When 'other specified' is selected the users are encouraged to specify the new item in an additional list ((10), p. 221). Accordingly, the participants insisted that some specifications be explicitly added to some 'other specified' categories in order to address essential and specific issues relevant to persons with sleep disorders (final code number '8').

Component Body Functions

Definitions: Body functions are the physiological functions of body systems (including psychological functions).

Impairments are problems in body function or structure as a significant deviation or loss.

About one third (30 out of 70 candidate categories) of the second-level ICF categories of the component Body Functions were included in the first vote with a high agreement among the participants. These categories include functions frequently impaired in people with various forms of sleep disorders, like temperament and personality (11), memory (12), blood pressure (13-14), or immunological system functions (15).

With respect to less consensual decisions taken, the following issues might be of interest:

ICF Component: Body Functions (b)		
ICF Chapter: Voice and speech functions (b3)		
2nd level ICF Category	Number of yes votes in plenary session (n=26)	Arguments recorded in plenary sessions 1 and 2
b330 Fluency and rhythm of speech functions	0 (excluded in plenary session 2)	excluded, although some participants mentioned it being impaired in sleep deprivation (16), in the narcoleptic patient during cataplexy, and in bi-polar patients (17).
ICF Chapter: Functions of the cardiovascular, haematological, immunological and respiratory systems (b4)		
b430 Haematological system functions	12 (excluded in plenary session 2)	not clear for the participants whether problems with hypoxemia are covered in this category, category was mentioned to be important when describing the raised haemoglobin levels and increased erythrocytes in some sleep apnea patients, and increased susceptibility to blood clotting (18).
ICF Chapter: Functions of the digestive, metabolic and endocrine systems (b5)		
b510 Ingestion	6 (excluded in	excluded, though being declared as specific for

functions	plenary session 2)	sleep apnea and pharyngeal swallowing (19).
b545 Water, mineral and electrolyte balance functions	10 (excluded in plenary session 2)	excluded, though iron deficiency in Restless Legs Syndrome (20) (part of the inclusion criteria of this category, which was read out in plenary) and water retention due to oedema was discussed in the plenary.
ICF Chapter: Genitourinary and reproductive functions (b6)		
b650 Menstruation functions	12 (excluded in plenary session 2)	unclear whether it is related to physiological changes, e.g. menopause (21) (in which case it was mentioned as indicator for sleep changes) or the actual body function, definition was read out and the category excluded, since as a menopausal symptom, participants felt it could be neglected
ICF Chapter: Neuromusculoskeletal and movement-related functions (b7)		
b760 Control of voluntary movement functions	12 (excluded in plenary session 2)	unclear to the participants whether this also relates to abnormal movement during cataplexy or parasomnias, sleep deprived patients experience a degree of clumsiness (may overlap with *b1470 Psychomotor functions*) and complex motor functions like driving might be covered here
ICF Chapter: Functions of the skin and related structures (b8)		
b830 Other functions of the skin	0 (excluded in plenary session 2)	It wasn't clear whether sweating would be covered under this category but participants decided it was to be considered under *b550 Thermoregulatory functions*, and hence excluded this category

Component Body Structures

Definitions: Body structures are anatomical parts of the body such as organs, limbs and their components.

Impairments are problems in body function or structure as a significant deviation or loss.

In the selection process of *Body Structures* several categories were included in the first voting round with a high agreement. The major decisions for in- and excluded categories are the following:

ICF Component: Body Structures (s)		
ICF Chapter: Structures of the nervous system (s1)		
2nd level ICF Category	Number of yes votes in plenary session (n=26)	Arguments recorded in plenary sessions 1 and 2
s110 Structure of brain	Included in working group session 1 votes	No arguments recorded
s140 Structure of sympathetic nervous system	6 (excluded in plenary session 2)	Is needed for pineal gland functioning - so melatonin secretion is dependent on sympathetic nervous system, Role of sympathetic nervous system in arousals, sleep apnea and in periodic limb movement not yet clarified
s150 Structure of parasympathetic nervous system	3 (excluded in plenary session 2)	Both s140 and s150 excluded since the functional problems (e.g. pineal gland function) associated with these systems seemed to be more important than the possible structural impairments.
ICF Chapter: Structures involved in voice and speech (s3)		
s310 Structure of nose	Included in working group session 1 votes	typically found to be impaired in persons with sleep-related breathing disorders (SRBDs) (22)
s320 Structure of mouth	Included in working group session 1 votes	

s330 Structure of pharynx	Included in working group session 1 votes	
s340 Structure of larynx	1 (excluded in plenary session 2)	Relevant in SRBDs since also connected to upper airway, Might relate to rare sleep disorder of catathrenia
ICF Chapter: Structures of the cardiovascular, immunological and respiratory systems (s4)		
s410 Structure of cardiovascular system	Included in working group session 1 votes	Directly included in first vote with its strong association to sleep disorders (23)
s430 Structure of respiratory system	Included in working group session 2 votes	No arguments recorded
ICF Chapter: Structures related to the digestive, metabolic and endocrine systems (s5)		
s580 Structure of endocrine glands	18 (included in plenary session 2)	Included despite controversies on whether function or structure were more important, since the pituitary and thyroid glands were considered central body structures relevant for sleep functioning (24-25).
ICF Chapter: Structures related to movement (s7)		
s710 Structure of head and neck region	Included in working group session 2 votes	part of a normal sleep assessment, neck circumference and general craniofacial morphology as important indicators for sleep-related breathing disorders

Component Activities & Participation

Definitions: Activity is the execution of a task or action by an individual. Participation is involvement in a life situation.

Activity limitations are difficulties an individual may have in executing activities.

Participation restrictions are problems an individual may experience in involvement in life situations.

A broad range of categories from the ICF component *Activities and Participation* was selected by the participants. This reflects the diversity of daytime problems associated with sleep disorders. The inclusion of many categories of the chapters 1: *Learning and applying knowledge*, chapter 7: *Interpersonal interactions and relationships*, and chapter 8: *Major life areas*, highlights the need for a detailed and systematic description of activities of daily living. The inclusion of numerous categories from the chapter 7 of Activities and Participation: *Interpersonal interactions and relationships* (e.g. bedpartners/co-sleeping(44-46), relationships(47-49) proxy ratings (50)) underlines this major aspect of the patient perspective.

Also, by including many of the categories from *Education* and *Work and employment* in the chapter 8: *Major life areas*, participants gave credit to these important aspects of the patient's lived experience which are also of great interest to public health, e.g. school performance (36-37) or work disability (38-43).

With regard to aspects of sleep hygiene, the following categories were highlighted and selected by diving onto the third level of hierarchy:

ICF Component: Activities and Participation (d)			
ICF Chapter: Self care (d5)			
2nd level ICF Category	3rd level category	Number of yes votes in plenary session (n=26)	Arguments collected in plenary session 3 and 4
d570 Looking after one's health *Ensuring physical comfort, health and physical*		17 (decision to dive in plenary session 3) 0 (decision to exclude 2nd level category in plenary session 4)	Evidence from preparatory studies distinguish these categories, Sleep hygiene should be explicitly highlighted in 'd578 other specified'

and mental well-being, such as by maintaining a balanced diet, and an appropriate level of physical activity, keeping warm or cool, avoiding harms to health, following safe sex practices, including using condoms, getting immunizations and regular physical examinations.	d5700 Ensuring one's physical comfort	Included in working group session 3 votes	participants decided sleep hygiene would be covered under d5700 in the definition wording 'ensuring, that one's body is in a comfortable position'
	d5701 Managing diet and fitness	Included in working group session 3 votes	Participants included d5701 in its relation to patients with sleep-related breathing disorders, insomnia and sleep deprived patients (connecting also to *b130 Energy and drive functions* and subcategory *b1302 Appetite*).
	d5702 Maintaining one's health	Included in working group session 3 votes	participants decided sleep hygiene would be covered under d5702 and it's definition: 'following medical and other health advice'.

Component Environmental Factors

Definition: Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives.

A large number of *Environmental Factors* was included in the Comprehensive ICF Core Set. Consistent with studies reporting the importance of the natural environment for sleep functioning, like *e225 Climate* (51), *e240 Light* (52) or *e245 Time-related changes* (53), *e250 Sound* (54) or *e260 Air quality* (55), participants included these categories as well.

But not only natural environmental factors make up the contextual range of issues covered by ICF. The inclusion of most of the categories from the chapter 3 *Support and relationships* and chapter 4 *Attitudes* again stress the important interdependency of functioning with the social environment (56-58). Of the chapter 5 *Services, systems and policies* many relevant categories like *e580 Health services, systems and policies* (59-60) and *e590 Labour and employment Services, systems and policies* (e.g. related to working conditions (61-62)) and more were included.

The importance of the following categories was especially highlighted by the experts by diving onto a third level of hierarchy:

ICF Component: Environmental Factors (e)			
ICF Chapter: Product and technology (e1)			
2nd level ICF Category	3rd level category	Number of yes votes in plenary session (n=26)	Arguments collected in plenary session 3 and 4
e110 Products or substances for personal consumption *Any natural or human-made object or substance gathered, processed or manufactured for ingestion.*		17 (decision to dive in plenary session 3) 0 (decision to exclude 2nd level category in plenary session 4)	Might want to consider that in insomnia there is the distinction between prescribed and over-the-counter drugs, need to specify nutrition, herbal medicine etc.
	e 1100 Food	Included in working group session 3 votes	No arguments recorded
	e 1101 Drugs	Included in working group	No arguments recorded

Inclusions: food and drugs		session 3 votes	
e115 Products and technology for personal use in daily living *Equipment, products and technologies used by people in daily activities, including those adapted or specially designed, located in, on or near the person using them. Inclusions: general and assistive products and technology for personal use*		18 (decision to dive in plenary session 3) 0 (decision to exclude 2nd level category in plenary session 4)	this would fit with assisted ventilation and other appliances used in sleep disorders might be adequately covered in the definition of 2nd level
	e 1150 General products and technology for personal use in daily living	Included in working group session 3 votes	'Furnitures' and 'textiles' etc used in wording of definition refers to which kind of bed or pillow is used.
	e 1151 Assistive products and technology for personal use in daily living	Included in working group session 3 votes	Includes 'functional stimulation devices that control breathing' in the category definition which might cover Continuous Positive Airway Pressure, Also covers intra-oral appliances and other appliances, With reference to clinical practice and for reimbursement physicians are required to report use of CPAP, Category necessary to check compliance with CPAP (although sleep hygiene category already exists)

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